

Understanding the longer-term experience of community inclusion for
wheelchair users following the 2010/2011 Canterbury earthquakes: A
mixed methods study

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Abstract

Background

The 2010/2011 Canterbury earthquakes and aftershocks in New Zealand caused unprecedented destruction to the physical, social, economic, and community fabric of Christchurch city. The recovery phase in Christchurch is on going, six years following the initial earthquake. Research exploring how disabled populations experience community inclusion in the longer-term recovery following natural disasters is scant. Yet such information is vital to ensure that recovering communities are inclusive for all members of the affected population. This thesis specifically examined how people who use wheelchairs experienced community inclusion four years following the 2010/2011 Canterbury earthquakes.

Aims

The primary research aim was to understand how one section of the disability community – people who use wheelchairs – experienced community inclusion over the four years following the 2010/2011 Canterbury earthquakes and aftershocks. A secondary aim was to test a novel sampling approach, Respondent Driven Sampling, which had the potential to enable unbiased population-based estimates. This was motivated by the lack of an available sampling frame for the target population, which would inhibit recruitment of a representative sample.

Methodology and methods

An exploratory sequential mixed methods design was used, beginning with a qualitative phase (Phase One), which informed a second quantitative phase (Phase Two). The qualitative phase had two stages. First, a small sample of people who use wheelchairs participated in an individual, semi-structured interview. In the second stage, these participants were then invited to a group interview to clarify and prioritise themes identified in the individual interviews.

The quantitative phase was a cross-sectional survey developed from the findings from Phase One. Initially, Respondent Driven Sampling was employed to conduct a national, electronic cross-sectional survey that aimed to recruit a sample that may provide unbiased population-based estimates. Following the unsuccessful application

of Respondent Driven Sampling, a region-specific convenience sampling approach was used. The datasets from the qualitative and quantitative phases were integrated to address the primary aim of the research.

Results

In Phase One 13 participants completed the individual interviews, and five of them contributed to the group interview. Thematic analysis of individual and group interview data suggested that participants felt the 2010/11 earthquakes magnified many pre-existing barriers to community inclusion, and also created an exciting opportunity for change. This finding was encapsulated in five themes: 1) earthquakes magnified barriers, 2) community inclusion requires energy, 3) social connections are important, 4) an opportunity lost, and 5) an opportunity found. The findings from Phase One informed the development of a survey instrument to investigate how these findings generalised to a larger sample of individuals who use wheelchairs.

In Phase Two, the Respondent Driven Sampling approach failed to recruit enough participants to satisfy the statistical requirements needed to reach equilibrium, thereby enabling the calculation of unbiased population estimates. The subsequent convenience sampling approach recruited 49 participants who, combined with the 15 participants from the Respondent Driven Sampling approach that remained eligible for the region-specific sample, resulted in the total of 64 individuals who used wheelchairs and were residents of Christchurch.

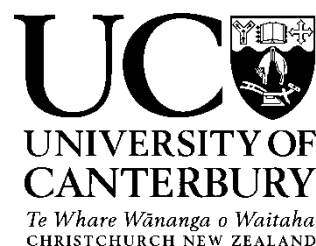
Participants reported their level of community inclusion at three time periods: the six months prior to the first earthquake in September 2010 (time one), the six months following the first earthquake in September 2010 (time two), and the six months prior to survey completion (between October 2015 and March 2016, (time three)). Survey data provided some precision regarding the timing in which the magnified barriers developed. Difficulty with community inclusion rose significantly between time one and time two, and while reducing slightly, was still present during time three, and had not returned to the time one baseline. The integrated findings from Phase One and Phase Two suggested that magnified barriers to community inclusion had been

sustained four years post-earthquake, and community access had not returned to pre-earthquake levels, let alone improved beyond pre-earthquake levels.

Conclusion

Findings from this mixed methods study suggest that four years following the initial earthquake, participants were still experiencing multiple magnified barriers, which contributed to physical and social exclusion, as well as fatigue, as participants relied on individual agency to negotiate such barriers. Participants also highlighted the exciting opportunity to create an accessible city. However because they were still experiencing barriers four years following the initial event, and were concerned that this opportunity might be lost if the recovery proceeds without commitment and awareness from the numerous stakeholders involved in guiding the recovery. To truly realise the opportunity to create an accessible city following a disaster, the transition from the response phase to a sustainable longer-term recovery must adopt a new model of community engagement where decision-makers partner with people living with disability to co-produce a vision and strategy for creating an inclusive community. Furthermore, despite the unsuccessful use of Respondent Driven Sampling in this study, future research exploring the application of RDS with wheelchair users is recommended before discounting this sampling approach in this population.

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An abbreviated version regarding the experience of testing a novel sampling approach in Chapter Five (particularly section 5.8.2, p. 140-142) was published in F1000Research (copy included, see Appendix S).

Bourke, J. A., Schluter, P. J., Hay-Smith, E. J. C., & Snell, D. L. (2016). Respondent driven sampling of wheelchair users: a lack of traction. F1000Research, 5(753), 1-18.

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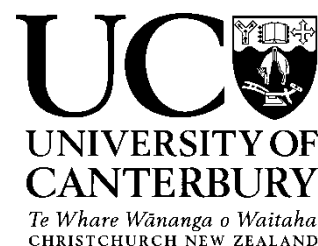
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Bourke, J. A., Hay-Smith, E. J. C., Snell, D. L., & Schluter, P. J. (2017). Community inclusion of wheelchair users during the long-term recovery phase following the 2010/2011 Canterbury earthquakes. International Journal of Disaster Risk Reduction, 23, 169-177.

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As per agreement, all publications arising from the research in this thesis includes supervisors as co-authors. For this publication, the contributions were: Bourke: 80%, Hay-Smith: 10%, Snell: 5%, Schluter: 5%.

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Name: *Philip Schluter* Date: *24th June 2017*

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F1000Research, 5(753), 1-18.

Bourke, J. A., Hay-Smith, E. J. C., Snell, D. L., & Schluter, P. J. (2017).
Community inclusion of wheelchair users during the long-term
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International Journal of Disaster Risk Reduction, 23, 169-177.

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List of Abbreviations

| | |
|------|--|
| ACC | The Accident Compensation Corporation |
| ADA | The Americans With Disabilities Act (US) |
| BACC | The Burwood Academy Consultation Committee |
| CCDU | The Central Christchurch Development Unit |
| CDHB | The Canterbury District Health Board |
| CERA | Canterbury Earthquake Recovery Authority |
| CIL | Centre Of Independent Living |
| CWS | CERA Well Being Survey |
| DAP | The Disability Action Plan |
| DDA | The Disability Discrimination Act (UK) |
| EDLG | The Earthquake Disability Leadership Group |
| HIV | The Human Immunodeficiency Virus |
| ICF | The International Classification Of Functioning And Disability |
| ISA | The International Symbol of Accessibility |
| M | Mean average |
| MoH | The New Zealand Ministry of Health |

| | |
|--------|--|
| MSD | The New Zealand Ministry Of Social Development |
| M_w | Magnitude of earthquake |
| NZDS | The New Zealand Disability Strategy |
| NZSCIR | The New Zealand Spinal Cord Injury Register |
| RDS | Respondent driven sampling |
| PAR | The Pressure And Release Model |
| SD | Standard deviation |
| SCI | Spinal Cord Injury |
| UK | The United Kingdom |
| UNCRPD | United Nations Convention for the Rights of People with Disabilities |
| UPIAS | The Union Of Physically Impaired Against Segregation |
| URL | Uniform Resource Locator (the address of a World Wide Web page) |
| USA | The United States of America |
| WHO | World Health Organization |

Chapter One: Introduction

Traditional infrastructure, day-to-day life, and emergency procedures are designed for people without disabilities. It is assumed that human bodies have four functioning limbs; five functioning senses; and the cognitive ability to observe, interpret, and respond to the world in a normative fashion. Society assumes normed functioning and often disregards those who walk, talk, or think atypically. Unfortunately, such marginalisation often leads to calamitous experiences during disasters – experiences that are rarely recorded. (Kelman & Stough, 2015, p. 3)

1.1 Setting the scene

Immediately following the severe February 22nd 2011 earthquake¹ in Christchurch, New Zealand, a wheelchair user battled to transverse the ruptured ground outside of their workplace, taking 20 minutes just to cover the 10 metres to their car. Once they made it home, they could not access their house, let alone enter it because the driveway was cracked and the doors were jammed. At the same time, another person who used a wheelchair remained without assistance because their support workers were unable to visit due to catastrophes of their own. This person was also without power for two weeks; power necessary to keep their wheelchair batteries charged, and specialised mattress inflated. Following the same earthquake, other people who used wheelchairs struggled to access the emergency accommodation shelters, find accessible temporary housing, accessible toilets and showers, and dealt with emergency organisations who struggled to understand and address their specific needs. These anecdotes following one of the many earthquakes during 2010/2011 in

¹ Over 14,000 aftershocks have been reported in the four years following the initial September 2010 earthquake. The most significant aftershocks are often described as earthquakes (Reyners, 2011). Throughout my thesis the term earthquake and aftershock are used for the most significant aftershocks synonymously.

Christchurch reflect a growing body of literature that suggests people who use wheelchairs, and people living with disability, are disproportionately vulnerable following natural disasters due to a variety of physical and social reasons. However scant research has examined how people who use wheelchairs experience the longer-term recovery phase following a disaster.

Indeed, disaster recovery is one of the least understood phases following natural disasters, and there is a paucity of research examining how people living with disability experience the longer-term recovery phase following disaster. There is also a need to understand the specific diversity amongst people living with disability following natural disasters. Disability is by no means the defining characteristic of a person, and people living with disability are indeed a very heterogeneous population. Understanding the specific needs of people with certain functional abilities, such as wheelchair users, can provide a more nuanced understanding of their experience during disaster recovery.

This thesis was motivated to address this gap in this literature, and specifically, to understand how wheelchair users in Christchurch, New Zealand, experienced community inclusion in the four years following the initial September 2010 earthquake. This thesis is based on the premise that it is necessary to create an accessible society that provides equal opportunities to the increasingly diverse composition of New Zealand's growing population.

1.2 Disability and disaster

Disability and disaster have become established fields of scholarship respectively. Before exploring the intersection of disability and disaster, it is worth noting that there are many parallels between each field. Three significant parallel themes include: the shared negative connotations, the fact that increasing numbers of people are affected by both disability and disaster worldwide, and more recent shifts in conceptualising both disability and disaster. In terms of negative connections, Kelman and Stough (2015) highlight how the *dis* in disability refers to a lack of ability; and in a similar vein the word (*dis*)aster can be traced to the root word 'bad star', implying that the experience of a disaster is orchestrated from the heavens. Dis is a Latin prefix meaning "apart", "asunder", "away", "utterly", or having a privative, negative, or

reversing force; used freely, especially with these latter senses, as an English formative. Secondly, both disability and disasters are affecting more people in the world. Over the last century, natural and technological disasters have occurred with increasing frequency (Misomali & McEntire, 2008). During the last thirty years, the number of reported natural disasters have increased four-fold, from approximately 100 in 1974 to over 400 in 2003 (Guha-Sapir, Hargitt, & Hoyois, 2004). With regard to disability, the World Health Organization estimates that in 2010 approximately one billion people (around 15%) of the world's population experienced disability, an increase from an estimated 10% in 1970 (World Health Organisation, 2011). Thirdly, the conceptualization of both disability and disaster has been more oriented to how societal forces can create 'disability' and 'disaster' (Oliver, 1990; Perry, 2006). For example, in the social vulnerability perspective, natural hazards discriminate against certain populations that are more vulnerable, perpetuating pre-existing inequalities during and after natural disasters (Thomas, Phillips, Lovekamp, & Fothergill, 2013). With regard to disability, there has been a move away from a biomedical conceptualisation of disability to how societal forces can create disability. As Kelman and Stough (2015) write 'we have constructed a world that is not inclusive of all abilities; thus creating disability. We have constructed a world that does not protect all from hazards; thus making some people experience disaster' (p. 11).

1.3 The intersection of disability and disaster

Research examining the intersection of disability and disaster is increasing. Research has focused on emergency preparedness and mitigation (Nicholls, 2015; Uscher-Pines et al., 2009), the response phase immediately following an event (Rowland, White, Fox, & Rooney, 2007), and coordinated and integrated rehabilitation preparation and planning (Sheppard & Landry, 2016). A further contribution to the literature was the work of Ilan Kelman and Laura Stough, who have recently edited a book length collection of first-hand accounts written by people living with disability regarding their disaster experiences (Kelman & Stough, 2015).

Research focusing on the intersection of disability and disaster suggests that people experiencing disability are disproportionately vulnerable during natural disasters (Fox, White, Rooney, & Rowland, 2007; Fox, White, Rooney, & Cahill, 2010; Priestley & Hemingway, 2007). Reasons reported for this included damaged infrastructure which

restricts mobility, inaccessible shelters and temporary housing options, requiring assistance to organise supplies and equipment, and dealing with emergency personnel who had little knowledge of disability needs and how to address those needs (Rooney & White, 2007; Rowland et al., 2007). This disproportionate vulnerability can be somewhat explained by the social vulnerability perspective, whereby pre-existing inequalities are unmasked through natural disasters (Hemingway & Priestley, 2006; Peek & Stough, 2010).

Also, disaster response plans are often designed for able-bodied people. People living with disability have traditionally experienced poor representation in emergency planning, thereby creating emergency organisations who struggle to understand the extent or specific nature of the issues that need to be addressed (Fox et al., 2007; Rowland et al., 2007).

Despite the growth of research in the field, a number of challenges still remain. Disaster recovery is one of the least understood areas of disaster research (Smith & Wenger, 2006), and this applies to the intersection of disability and disaster. There is scant research exploring the perspectives of people who experience disability over the longer-term recovery phase following a disaster. While some work has explored recovery at six months (Fox et al., 2010), and two years following a disaster (Stough, Sharp, Resch, Decker, & Wilker, 2016), more research is needed to understand the longer-term ramifications for people living with disability during the recovery phase following disasters. Phillips (2015) notes that the recovery phase following a disaster often follows a blurry timeframe, and the recovery process can remain considerably uneven, particularly so for historically marginalised populations, including people living with disability, who may languish during this process.

Second, there is a need to produce more direct accounts of how people living with disability experience disaster. First hand narratives from people living with disability constitute a small yet increasing voice in disaster recovery research (Fox et al., 2007; Rooney & White, 2007; Stough et al., 2016). Kelman and Stough (2015) contend it is imperative to continue to accumulate reports of the personal experience of individuals with disabilities in disaster contexts to ‘give voice’ to the social vulnerability perspective, and challenge the narrative that people living with disability are passive victims in post-disaster contexts (p. 177).

Furthermore, there is a need to conduct more robust epidemiological research in the area of disability, including the intersection of disability and disaster. At first glance, disability and epidemiology appear to occupy conflicting territory. Traditional epidemiology, with its established connotations of biological causation of health and illness, and focus on prevention and reduction of disease (Gerstman, 2013; Rothman, Greenland, & Lash, 2008), appears to represent regression to the medicalisation of disability, where disability is synonymous with biological pathology and ill health. However increasingly holistic definitions of what constitutes health, challenges the fields of epidemiology and public health to expand and develop ways to better understand the social and environmental determinants of disability (Andresen, 2011; Möller, 2015). In responding to this challenge, epidemiology can provide a valuable contribution to understanding the complex manifestation of disability in the community through “the study of the distribution, determinants, correlates, and outcomes of disability and application of this study to maximizing the health, participation, and quality of life of people and populations with disability” (Andresen, 2004, p. 1).

This builds into a further issue often discussed at the intersection of disability and disaster: fundamental human rights. From a human rights perspective, all members of society should be subject to equity of services, and access regardless of the presence of disasters. In an effort to regulate the ethical stance of equality for people living with disability, there is increasing legislation around the world, such as the 1990 Disabilities Act in the United States, and the 1995 Disability Discrimination Act in the United Kingdom. Furthermore, efforts such as the United Nations Convention for the Rights of People with Disabilities (UNCRPD), contribute to the argument for equal rights and opportunities for people living with disability. Understanding the experience that people living with disability face in post-disaster contexts can provide insight into how people living with disability experience society in non-disaster contexts. As Kelman and Stough (2015) write: “at the intersection (of disability and disaster), we find broader issues that underlie how society deals with people” (p. 183).

1.4 A recent disaster in New Zealand: the Canterbury earthquakes and aftershocks

New Zealand is situated in the southwest Pacific region, and comprises two main islands: the North Island (Te Ika-a-Māui) and the South Island (Te Waipounamu). The Canterbury region is on the South Island's central east coast, and Christchurch is the island's largest city (third largest in the country behind Auckland and Wellington) with a population reported in the 2013 Census of 341,469 (Statistics New Zealand, 2013).

New Zealand is recognised as being prone to earthquakes due to its position between two tectonic plates: the Pacific plate to the east, and the Australasian plate to the west (Gledhill, Ristau, Reyners, Fry, & Holden, 2011). Correspondingly, several large earthquakes have occurred in the central South Island over the last 150 years, including a M_w (magnitude) 7.1 in 1888, a M_w 7.0 in 1929, a M_w 6.7 in 1994, and a M_w 6.2 in 1995 (Gledhill et al., 2011).

The 2010/2011 Canterbury earthquake sequence began at 4:35am on 4 September 2010 when a M_w 7.1 earthquake struck near the small town of Darfield, 40kms east of Christchurch city. The September earthquake caused extensive damage to buildings and infrastructure in Christchurch city and fortunately no associated deaths occurred (Potter, Becker, Johnson, & Rossiter, 2015). Following the September earthquake Canterbury experienced a catastrophic M_w 6.3 earthquake at 12:51pm on 22 February 2011. The February earthquake struck 6kms southeast of Christchurch city, at a depth of 5kms. The February earthquake caused extreme ground acceleration relative to the magnitude, resulting in disastrous damage to buildings and the physical environment of Christchurch city (Reyners, 2011). The combination of ground acceleration, time of day, and proximity to the CBD of Christchurch resulted in a number of injuries and deaths. The February earthquake claimed 185 lives, and at least 7171 people were injured (Potter et al., 2015). Four more significant aftershocks struck, two on 13 June 2011, (M_w 6.3 and 6.0 respectively) and two on 23 December 2011 (M_w 5.8 and 5.9 respectively), which were not fatal but caused further disruption to the physical

environment of Christchurch. Four years after the September 2010 earthquake more than 14,164 aftershocks have been reported² (Morton, 2015).

Christchurch has experienced a complex and extensive recovery, which is ongoing. Three quarters of the housing stock in the Canterbury region experienced damage, and over 600 commercial buildings in the central business district were demolished. Over 500,000 tonnes of silt, known as liquefaction, was ejected from below the surface of Christchurch during the February earthquake, causing severe damage to roads, water, electricity, and sewage infrastructure (Morgan et al., 2015). The total recovery cost has been estimated as being in the vicinity of \$40 billion (New Zealand Treasury, 2013; Potter et al., 2015). The social and community impact of the Christchurch earthquakes was extensive, with those identifying as living with a health condition or disability more likely to report increased levels of stress, and less likely to rate their lives positively (Canterbury Earthquake Recovery Authority, 2015c).

Research exploring the experience of people living with disability following the 2010/2011 Canterbury earthquakes reported similar findings to those in the international literature. People experiencing disability were generally not prepared for a disaster before the 2010 September earthquake, and faced a number of challenges after the earthquake (Brereton, 2012; Phibbs, Woodbury, Williamson, & Good, 2012). People experiencing disability in Canterbury reported that a lack of accessible interim accommodation and housing was a major issue, with 63% reporting that they had to evacuate their homes (Phibbs et al., 2012). Furthermore, accessing necessary supplies, and inaccessible buildings, toileting facilities, emergency stations, and disrupted public transport were all problematic issues (Brereton, 2012). For those with mobility impairments who could not drive, the closure of supermarkets and other businesses (especially in the eastern suburbs) meant that trips to shops and appointments required more organising, and were more expensive and time consuming. People experiencing

² Following the completion of my data collection, a Mw 7.8 earthquake struck on 14 November 2016 in Culverden, approximately 95 km north-east of Christchurch and 60 km south-west of the tourist town of Kaikoura. This earthquake was a larger magnitude than the two Canterbury earthquakes, and the second largest recorded since European settlement. There were two deaths and over \$900 million in insurance claims have been received (Quigley & Duffy, 2016).

disability had trouble accessing welfare centres. Concerns included accessing transport to the welfare centre, access into and within the centres, hygiene, attitudes, and having specialised equipment (beds and hoists) inside the centres (Brereton, 2012; Phibbs et al., 2012).

1.5 Disability in New Zealand

The number of people who experience disability in New Zealand is increasing. The 2013 New Zealand Disability Survey estimated that 1.1 million people reported a disability³, representing 24% of the total population, an increase from 17% reported in 2006 (Statistics New Zealand, 2014). More specifically, the number of wheelchair users is unknown. However, some indication can be drawn from the 2013 New Zealand Disability Survey (Statistics New Zealand, 2014), which reported that 13% of the national population (551,466 people) identified as having a mobility impairment. At a regional level, the same survey reported that approximately 143,000 people in Canterbury identified as living with disability, of whom 12% (17,160 people) reported having both a mobility impairment and residing in a private dwelling (Statistics New Zealand, 2014).

Government policy in New Zealand requires the building of an inclusive society (New Zealand Disability Strategy, 2001). The New Zealand Bill of Rights (1990), the Human Rights Act (1993), and the New Zealand Disability Strategy ensure that central and local government, including state owned enterprises, have a responsibility to avoid the discrimination of people based on impairment or disability and create a fully inclusive society.

Government legislation also requires that the construction of, and alteration to, any buildings, premises, facilities to which members of the public are to be admitted, either free or by way of charge, must comply with section 118 of the Building Act 2004 (Ministry of Business Innovation and Employment, 2004). Section 118 states that building consent authorities must not grant consents for the construction and

³ The 2013 NZ Disability Survey defined disability as: “an impairment that has a long-term, limiting effect on a person’s ability to carry out day-to-day activities”. Long term is defined as six months or longer.

alteration of buildings unless satisfied that “reasonable and adequate provision by way of access, parking provisions, and sanitary facilities are made for persons with disabilities who may be expected to visit or work in that building, and/or carry out normal activities and processes in that building” (Ministry of Business Innovation and Employment, 2004, p. 113). Furthermore, in 2007 New Zealand signed The United Nations Convention on Rights of Persons with Disabilities, which requires the full realisation of all human rights and equal opportunities for all people who experience disability, without discrimination of any kind (Office for Disability Issues, 2016).

Despite this inclusive legislative position, whether people who live with disability experience equality is questionable. For example, a recent United Nations review reported that people who live with disability in New Zealand still experience barriers accessing health services, education, and employment. Furthermore there appeared to be limited support and services in place enabling people who live with disability to exercise the choice to be included in the community (United Nations Committee on the Rights of Persons with Disabilities, 2014). This raises concerns regarding the degree to which New Zealand does indeed have an inclusive society, and necessitates research to understand how people who live with disability experience the community.

1.6 Purpose and aims of thesis

To advance the knowledge base regarding the intersection of disability and disaster, more research is needed which examines the direct accounts of people living with disability during the longer-term recovery phase post-disaster. In addition, new methodologies that enable robust epidemiological research to be conducted can help unpack the complex and multi-layered manifestation of disability after disaster situations.

This thesis aims to extend the literature through addressing these challenges. My research explores the intersection between a particular hazard type (earthquake), population (wheelchair users), and timeline (the recovery phase 4 years post-disaster). The specific research question that this thesis aims to explore is:

How have one section of the disability community – people who use wheelchairs –experienced community inclusion over the four years following the earthquakes in 2010/2011 in Canterbury New Zealand?

To address the question I chose to use an exploratory sequential mixed methods design which began with a qualitative phase, followed by a quantitative phase. Beginning with a qualitative phase was considered appropriate due to the paucity of research regarding the longer-term experience of people living with disability following disasters. Due to the newness of the research topic, I felt a qualitative enquiry would enable the interpretation of unique perspectives regarding participants' contextual experiences. The second, quantitative phase of my research was envisioned to build upon the first phase, through seeking to understand the prevalence of Phase One findings and the relationships between important variables in a larger sample. Furthermore, the second quantitative phase provided an opportunity to address existing methodological challenges regarding the recruitment of representative samples in disability research. Rich, qualitative inquiry exploring the direct narratives of wheelchair users, combined with robust epidemiology research can help to address what Alexander (2015) refers to as the 'adoption gap' between policy, and what is *actually* practised following a disaster (p. 25). Such evidence can help ensure that all members of a population are afforded equal opportunities to live independent, productive lives as communities recover post-disaster.

In regard to the specific population I sampled, I focused on people with specific functional needs: people who use a wheelchair as their main form of mobility, as opposed to the entire population of 'people living with disability'. A key reason for this decision was that the variety of factors that contribute to disability, combined with challenges defining disability, make it very difficult to determine who qualifies, or indeed identifies, as a 'disabled person' (Barnes & Mercer, 2003). For example, using the social model argument that disability manifests in the barriers and oppression that society can impose on people with various impairments, a disabled person could by definition include a person with a broken arm, a severe brain injury, total vision impairment, learning difficulties, an obese person, an elderly person or someone with cancer. While it is imperative to celebrate the diversity of people who

live with disability, it is also necessary to understand the unique experience of people with certain functional needs who constitute part of the diversity of people who live with disability.

In regard to timeframe, I focused on the four years post-earthquakes primarily because very little research has explored the inclusion of people living with disability, or indeed people who use wheelchairs in the longer-term recovery phase after a natural disaster. Furthermore, this timeframe enables an opportunity to potentially understand whether New Zealand legislation that supports the building of an inclusive society, where people living with disability are treated equally, has been applied to the real-world experience of people living with disability.

1.7 Thesis structure

This thesis comprises six chapters. In Chapter One I provide an initial overview of the context in which my research is situated. A brief description has been provided regarding the intersection of disability and disaster, how people living with disability experience disasters (with a specific focus on wheelchair users), and remaining challenges in the field. The New Zealand context has also been described, including the Canterbury earthquakes, the prevalence of disability in New Zealand, and the legislative framework surrounding disability in New Zealand. Altogether, the content of Chapter One sets the scene and describes the gap in the literature which my research intends to address.

In Chapter Two I provide a much more detailed examination of the literature surrounding disability and disasters. Disability is a complex lived experience and field of study, and in Chapter Two I attempt to provide the reader with an overview of the key ways in which disability is conceptualised. The individual, social, minority, and cultural models are all described. An examination of theory and empirical research exploring disability in short-term disaster recovery is also provided, including research and policy initiatives surrounding disability and the Canterbury earthquakes. The small amount of research that has explored disability and longer-term disaster recovery is also examined. Key social theories surrounding disabled persons' vulnerability in disaster contexts are described. Finally, I discuss some of the methodological challenges in undertaking epidemiological research with disability,

especially regarding recruitment and the frequent reliance on convenience based samples fraught with non-sampling biases.

In Chapter Three I outline the methodology and methods used in this thesis. Focus is given to the research question, the mixed methods research design considered appropriate for such question, the theoretical assumptions underpinning the research design, and cultural and ethical considerations. Particular emphasis focuses on why the combined use of the pragmatist paradigm (answering research questions in practical, action orientated ways), and the transformative paradigm (conducting research that promotes social justice) was considered an appropriate foundation for mixing a qualitative and quantitative method in my research project.

In Chapter Four I outline Phase One of the research design. In this qualitative phase 13 individual semi-structured interviews were conducted with people 16 years or older who use wheelchairs, followed by a group interview with five of the 13 participants. Thematic analysis was used to interpret themes within the data. These themes were used to inform the development of the survey used in Phase Two.

In Chapter Five I document Phase Two of the research design. This chapter I specifically explored how the survey was developed, pilot tested, and administered. In Chapter Five I also describe the rationale and use of a novel chain-referral sampling approach: Respondent Driven Sampling (RDS). The unsuccessful use of RDS is examined, including reasons why it may have failed, and potential ways of avoiding such failure in the future. The subsequent use of a convenience sampling approach and a detailed analysis of the survey findings are also described in this chapter.

In Chapter Six I integrate and present an interpretation of the findings from both phases, examining the ways in which the datasets complement and/or diverge from one another in relation to the research question. A critical emphasis is placed on interpreting findings in ways that provide conclusions greater than the sum of the individual research components. In Chapter Six I specifically outline the ways in which the findings extend the literature in the field through providing evidence that multiple, environmental barriers to community inclusion are still present for people who use wheelchairs four years after the initial earthquake. Despite participants still experiencing community exclusion, an unprecedented opportunity to create an

accessible community exists. The argument is presented that strategies and solutions focusing on creating an accessible and inclusive community, are co-produced through partnership between decision-makers and people experiencing disability to ensure a sustainable, inclusive community. This chapter also presents the strengths and limitations of the research.

In Chapter Seven I present the overall conclusions of my research and propose directions for future research in the field of disability and longer-term recovery following disaster.

1.8 Terminology

There is spirited debate regarding the terminology surrounding disability and how best to describe people who live with disability. For example, it is common for scholars based in the UK tradition of the social model to use the term ‘disabled people’, to represent the idea that society *disables* people through a variety of structural and material forces which manifests in restrictive and discriminatory environments. Conversely, others choose to use the term ‘people with disabilities’ to promote *person-first* language, whereby disability is a secondary trait of an individual. I have reflected for many years on how I choose to describe disability throughout my study and teaching, and importantly, as a person who uses a wheelchair and has experienced disability. I have chosen to proceed with the term “people who live with disability”. I prefer this term as it combines person-first language (which I value), with the idea that ‘disability’ can be socially constructed and not necessarily an entity that ‘belongs’ to an individual. So, throughout this thesis I use the term people living with disability.

1.9 Summary

Despite an established base of knowledge examining the intersection of disability and disaster that contends that people living with disability experience disproportionately negative outcomes following natural disasters, a number of challenges in the field remain. A further significant factor of this thesis is that I share many things with the participants in the study. I live with disability, use a wheelchair as a result of spinal cord injury (SCI), reside in Christchurch, and have experienced many of the 2010/2011 earthquakes (see section 3.5 researcher position).

Chapter Two: Disability, Community, and Disaster

2.1 Introduction

This chapter provides the context for this thesis by providing background to the topic of disability and disaster. Information in this chapter was identified by a review of the literature surrounding disability, community, and disaster. Specific attention was given to how people living with the experience of disability experienced post-disaster contexts with regard to recovery and community inclusion. Exploring this literature helped to identify patterns regarding how people living with disability experience post-disaster recovery, and also helped to identify gaps in the literature that require more investigation. Because the focus of my research was community inclusion during the longer-term recovery phase following a disaster, literature concerning the emergency management of injuries and the medical rehabilitation immediately following natural disasters were excluded.

To identify relevant literature the following search terms were used: wheelchair*, Disab*, paraplegi*, tetraplegia*, quadraplegi* AND/OR disaster*, earthquake*, disaster recovery, recovery, accessibility, communit*. The following databases were searched: Pubmed, Medline, Cinhal, Scopus, Web of Science, Science Direct, Sage journals online. Specific journals were also searched, included *Disability and Rehabilitation*, *Disability and Society*, *Disasters*, and *The International Journal of Disaster Risk Reduction*. The reference lists of relevant articles and textbooks were also hand-searched. Abstracts were scanned and the full-text article downloaded and read if it was considered relevant to the aims of my research. A search of the grey literature was also performed through entering the above search terms into Google, and Google scholar.

The first section of this chapter examines disability and community as they are conceptualised independently from disasters. It is hoped this will provide the reader with a fundamental understanding of both concepts, as they will feature frequently throughout this thesis. The second section is an exploration of the interaction between disability and disaster, specifically the preparedness of people living with disability in disaster contexts, the social factors influencing the experience of people living with disability following disasters, and research regarding the Canterbury context. The

third section of this chapter examines a particular methodological challenge in disability research: recruiting a representative sample in quantitative research.

2.2 Disability and community

To provide context for my research, it is necessary to first provide a brief overview of the various ways in which disability, community, and the interaction between the two are conceptualised within the literature. The concept of disability has changed throughout the twentieth century and a concrete definition, despite many attempts, is still elusive. Broadly, disability has moved from being a concept defined from a medical viewpoint, to a concept instead determined by a myriad of social and political influences. Definitions of community and community inclusion have also been difficult to determine. However there is broad agreement that community involves interactions between people and their environments, and that community inclusion refers to having equal opportunities to engage in social relationships, social roles, and cultural, economic, and political activities. People living with disability have traditionally faced many barriers to community inclusion, and despite positive policy developments in many countries in recent decades promoting equal participation of people living with disability, such efforts have not always translated in practice.

2.2.1 Conceptualising disability

In this section I outline the various ways in which disability has been understood throughout the last century. Disability has long been understood from a medical viewpoint, the repercussions of which still exist in contemporary society. However, since the 1960s, disability has taken on a more political identity, influenced by the social movements of the time. Disability studies is now a recognised field in academia, and many involved in the field engage in robust debate regarding what disability is and how we should respond to disability.

The individual/medical model of disability

For much of the twentieth century, a ‘disability’ was something people ‘had’. Disability was seen as a problem located in a person’s body. Scientific medicine, legitimised by the state, was indeed the authority on the body, and determined differences between ‘normal’ and ‘abnormal’ bodies, in turn medicalising the concept of disability (Oliver, 1990). The fundamental cause of any disability a person

experienced was a direct result of physiological and functional abnormalities, which rendered a person as deviating from what was considered normal function (Barnes & Mercer, 2003). A further consequence of this viewpoint was that disability was considered a ‘tragic’ event in that a person’s biological deficit was the fundamental reason for that person’s social exclusion. (Barnes & Mercer, 2010; Goodley, 2011). Any mismatch between a person and their physical and social environments was attributable to a person’s impaired body.

An important implication of the individual/medical model is that any solutions, interventions, or ‘treatment’ for disability are directed at the level of the individual. Disability was an attribute of the individual “that had to be prevented, treated, or cured” (Barnes & Mercer, 2010, p. 24). Such an ideology informed a social policy emphasis on rehabilitation, service provision and interventions aimed at an individual level, with a focus on attaining as close as possible ‘bodily norms’ (Barnes & Mercer, 2003; Hammell, 2006; Prilleltensky, 2006). It was thus the responsibility of the disabled person to take heed of the professional expertise of rehabilitation and health professionals, in order to best adapt themselves to interact within their environment.

The framing of disability from a medicalised viewpoint influenced sociological theories of disability. For example, the sociologist Talcott Parsons argued that people living with disability (which he viewed as a chronic illness) constituted a deviance that disrupted the function of society, and developed the term of ‘the sick role’ to describe the social obligations expected of those presenting with chronic illness (Thomas, 2007). In return for being unproductive members of society, people with chronic illnesses were expected to do everything possible to get well, and to seek and follow medical advice.

A new vision of disability that emerged in the latter half of the twentieth century challenged the individual/medical framing of disability. People living with disability and disability advocates argued strongly that disability was not a problem located within a person's body, but instead occurred when political and social structures restricted the opportunities of people with impairments.

The social model of disability

The foundation for a social analysis of disability developed during the 1970s and was driven by people living with disability themselves who were frustrated with the lack of opportunities they experienced in society (Barnes, 2012). In England, advocates such as Paul Hunt argued that the social values of the time were directed towards the interests of the able-bodied population, and that this was a greater cause of oppression than a person's functional limitations (Barnes & Mercer, 2003; Finkelstein, 1991). Also in the 1970s, Ed Roberts and others in the United States (US) campaigned for the right to live on university campuses in the community with the help of assistants, paving the way for the first Centre of Independent Living (CIL) at Berkeley in 1972 (DeJong, 1979).

The Union of the Physically Impaired Against Segregation (UPIAS), founded in England in 1976, famously outlined the distinction between *impairment* and *disability*. An impairment was defined as the biological complications that a person experiences. However, disability occurred when the politics, environment, and social values of a society restricted, discriminated and/or excluded the opportunities of people with impairments (Union of Physical Impaired Against Segregation, 1976). This distinction 'broke the causal link between impairment and disability' (Barnes & Mercer, 2010, p. 30).

An often-used example to illustrate the social model is the presence of stairs to enter a building for a person using a wheelchair. A traditional view of disability would consider the problem to be that of the person's functional impairment that requires them to use a wheelchair. Advocates of the social model would argue that structural forces, such as the regulatory framework, create inaccessible buildings for wheelchair users. This barrier could be potentially eliminated through political action that required mandatory access to all buildings.

Of course the social model highlights more than just physical barriers, and focuses on how social, economic, cultural, political, and environmental barriers can oppress people with impairments. These barriers can prevent people living with disability from accessing housing, employment, education, and participating in a variety of life roles available to the non-disabled population. Further changes associated with the social model included the change in focus from charity to rights; enabling people living with disability to have more control in disability organisations; and lobbying

for change at a political level (Baird, Rosenbaum, & Toombs, 2009; Beatson, 2004; Oliver, 1990).

Beyond the social model of disability

The social model of disability has been referred to as the ‘big idea’ in disability studies of recent decades (Hasler, 1993), and has advanced the position of people living with disability in society through its focus on removing physical, economic, cultural, and political barriers within society. It has also influenced the way disability is conceptualised at a global level, for example the World Health Organisation’s (WHO’s) International Classification of Functioning, Disability, and Health (discussed below).

However, whether the social model is still the most appropriate method of conceptualizing disability has attracted debate. The most common concern of the social model is the almost exclusive focus on social structure at the expense of acknowledging the role that impairment plays in the experience of being disabled (Morris, 1991; Shakespeare & Watson, 2002). For example, feminist writers such as Jenny Morris argued that while societal values did indeed prejudice people living with disability, physical experiences such as pain and fatigue are real and disabling factors, and that to deny these crucially important physical aspects of the lived experience of disability was to only “collude in our oppression” (Morris, 1991, p. 183). Shakespeare (2014) argued that it is unfortunate that anything that appears to contradict the social model, i.e. reference to the importance of medicine or the individual experience of physical discomfort, is considered ‘inappropriate, misguided, or even oppressive’ (p. 31). Such arguments have led to calls to ‘bring the body back’ into disability studies, and that understanding the complexity surrounding the lived experience of disability requires the acknowledgement of social *and* physical factors.

Advancing a more nuanced understanding of disability by no means involves a rejection of ideas within the social model. To the contrary, many argue that achieving a more complete understanding of disability still requires key ideas about disability “that saw the light of day with the ascendance of the social model” (Meekosha & Shuttleworth, 2009, p. 50). For example, the social model has been instrumental in helping to conceptualise how society can disable people, which is still a real and

relevant concern in contemporary society. Indeed, Shakespeare (2014) argues that a critical revision of the social model does not mean a return to the “bad old days” where disability is medicalised; there are many different ways of conceptualising disability that “retain a commitment to equality and justice for disabled people” (p. 28).

Other models of disability that locate the individual in their social context also contribute to the understanding of disability. For example, the minority model and the relational model of disability both frame an exclusively individual approach to disability as inadequate, and both models share a political commitment to advancing the rights of people living with disability through the removal of socio-political barriers to social inclusion. The minority model asserts that people living with disability hold a minority position in society alongside other discriminated groups such as racial minorities and gay communities. The minority model focuses on how people living with disability form a population that is denied civic rights because they do not conform to ideas of ‘normality’ in the dominant individualism culture that is predominant in North American and Canadian societies (Goodley, 2011; Mitchell & Snyder, 2012). The relational model is a product of the Nordic countries and focuses on three key assumptions: 1) disability is a person/environment mismatch, 2) disability is situational and contextual, and 3) disability is relative. The relational model acknowledges that societal barriers can discriminate, and acknowledges individual and impairment effects, without reducing disability to either social or physical issues (Shakespeare, 2014).

Another approach is the cultural model of disability, which stems from disability studies researchers in North America (Shildrick, 2012). The cultural model emerged from the field often referred to as critical disability studies. In contrast to the social model focus on material determinants of disability, such as the distribution of political and economic resources, the cultural model of disability is more concerned with post-structural theories of disability. For example, cultural representations of disability in art and media, deconstructing the dichotomy between impairment and disability, analysing discourse surrounding disability, and exploring embodiment and the body as a place of ‘complex cultural production’ (Goodley, 2012, p. 635). Writing about the relevance and importance of the cultural model of disability in disability studies

scholarship, Shildrick (2012) argued that our understanding of all bodies is affected when considering the difference of disability, and that:

each of us, however we are embodied, is complicit in the construction and maintenance of normative assumptions, (and) it challenges every one of us to rethink the relations between disabled and non-disabled designations – not just ethically as has long been the demand, but ontologically, right at the heart of the whole question of self and other (p. 30).

The International Classification of Functioning, Disability, and Health

In 2001 the WHO developed the International Classification of Functioning, Disability, and Health (ICF), designed as an epidemiological tool that aimed to provide an international language to help conceptualise functioning and disability from the perspective of health (Bickenbach, 2012). The ICF also aims to provide a synthesis of the medical and social models of disability in order to ‘provide a coherent view of different perspectives of health from a biological, individual, and social perspective’ (World Health Organization, 2001, p. 20). As Dahl (2002, p. 202) suggested

“...the ICF is in line with modern understanding of ‘disability’ and ‘functioning’; disability not only is a consequence of a health condition, but is also determined by the physical environment, the services available in the society, attitudes and legislation, which are all environmental factors in that respect”.

The ICF has six components to classify a person’s profile (see Figure 2.1). These include the health condition, body functions and structures, activities (the execution of a task or action by an individual), participation (the involvement in a life role), environmental factors, and personal factors. These components are then divided into two parts: functioning and disability (that include body structures and functions, and activities and participation), and contextual factors (including environmental factors and personal factors). Functioning is an umbrella term for body functions, activities, and participation, whereas disability is an umbrella term for the ‘negative’ aspects of those domains, e.g. impairments, activity limitations, and participation restrictions (World Health Organization, 2001).

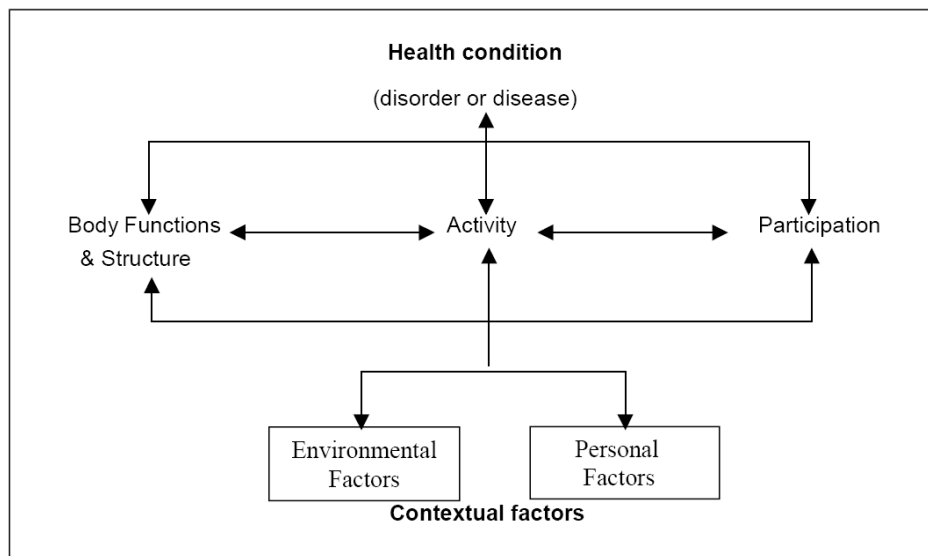


Figure 2.1. Interaction between components in the ICF (World Health Organization, 2001).

The ICF is not a complete solution to classifying factors surrounding disability, health, and functioning and attracts a range of criticisms. Many have highlighted the difficulty distinguishing between the domains of activity and participation (Bickenbach, 2012; Dahl, 2002). Further concerns include the lack of ability in the ICF to attach subjective meaning to both quality of life and participation goals, and that the ICF fails to inadequately conceptualise the constructs of participation and environment (McPherson, 2006; Whiteneck & Dijkers, 2009). At a more fundamental level, the ICF has been criticised as a classification framework based on social norms for whom people living with disability are positioned as deviating from (Barnes & Mercer, 2010; Hammell, 2006). If anything, these criticisms demonstrate the intense difficulty that exists in trying to gain consensus operationalising the factors surrounding disability.

The wheelchair as a symbol of disability

The role of the wheelchair in conceptualising disability has a chequered past. There is no doubt that the technological development of wheelchairs and the emergence of the power wheelchair has enabled people with mobility impairments to exercise more independence and engage in the community. However as a symbol of disability, the wheelchair can promote an unrealistic ideal of what disability represents, and fail to

acknowledge the complex and diverse experience of other people who live with disability. The wheelchair has come to symbolise what it is to be 'disabled', imagining disability is more often than not imagining the use of a wheelchair (Titchkosky, 2011). The most pragmatic realisation of this is the International Symbol of Accessibility (ISA): a white outline of a person sitting in a wheelchair against a blue background. This conceptualisation of disability can promote education and accessibility. However it is also a universal and narrow concept of what disability is, and what disability is not.

Using a wheelchair is subject to a variety of different interpretations, and many people require the use of a wheelchair for a great variety of reasons. Some people may use a wheelchair for a short period of time, while other people for only a small portion of the day or for certain tasks, whereas others require the use of a wheelchair as their main, and indispensable, form of mobility. For this reason, research involving wheelchair users generally relies on self-report definitions of wheelchair use.

Research in the USA and UK report that the prevalence of wheelchair users has rapidly increased over the last half century due, in part, to advancing medical care, ageing populations, increasing community support enabling deinstitutionalisation, increasing prescription of wheelchairs, and changes in attitudes to disablement such that people may feel less stigmatised about using a wheelchair (Russell, Hendershot, Le Clere, Howie, & Alder, 1997; Sapey, Stewart, & Donaldson, 2005).

To summarise, the concept of disability is subject to a myriad of definitions and interpretations that make a clear understanding difficult to articulate. Despite the differences in the models and frameworks above, it can be argued that a shared aim of all disability studies is a commitment to improving the lives of people living with disability through a greater understanding of factors involved in constructing disability. This could be through understanding and removing material barriers to social inclusion, or exploring cultural representations, and the role of discourse surrounding disability. For a description of disability and disability research as it is conceptualised for the purposes of this thesis see Chapter Three (section 3.2).

2.2.2 Conceptualising community

In this section I examine the concepts of community and community inclusion, with a specific focus on people living with disability, drawing on many of the ideas presented in the previous section.

Community

Much has been written about the term ‘community’, which has been described as “a slippery notion” to articulate (Vallance & Carlton, 2015, p. 2). At a broad level community is often described in an ecological sense as the interactions between people and their built, natural, social, and economic environments (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012; Nelson & Prilleltensky, 2005; Norris, Stevens, Pfefferbaum, Wyche, & Pfefferbaum, 2008; Overmars-Marx, Thomese, Verdonschot, & Meininger, 2014). Nelson and Prilleltensky (2005) suggested that community can be understood at four levels: the individual (e.g. identity), the micro-level (e.g. family), meso-level (e.g. work-settings), and macro-level (e.g. social policy, social norms).

A precise definition of ‘community inclusion’ is also elusive, and the term is often used interchangeably with social inclusion and participation (Overmars-Marx et al., 2014). Nelson and Prilleltensky (2005) defined community inclusion as “embracing and integrating people from diverse backgrounds into community” (p. 44). Cobigo et al. (2012) conducted a multidisciplinary, synthesis review of literature surrounding social inclusion of people with intellectual and developmental impairments and concluded that inclusion should be defined as:

A series of complex interactions between environmental factors and personal characteristics that provide opportunities to 1) access goods and services, 2) experience valued and expected social roles of one’s choosing based on their age gender, and culture, 3) be recognised as a competent individual and trusted to perform social roles in the community, and 4) belong to a social network within which one receives and contributes support. (p. 82)

This definition of community inclusion can be further understood through exploring the opposite concept – definitions of community *exclusion*. For example, Thomas

(2007) wrote that to experience social exclusion is to “not have access to rights and resources taken for granted by the majority” (p. 10), and that this resulted in disadvantage and a denial of citizenship. People living with disability have experienced many instances of structural exclusion and segregation from ‘mainstream’ society. For example, people living with disability typically resided in institutional care homes, received education via ‘special needs’ classes, and were employed in sheltered workshops (Barnes, 2012; Barnes & Mercer, 2003; Finkelstein, 1991; Tennant, 1995; White, 2003). However a complex variety of factors have challenged this position, including, but not limited to: the deinstitutionalisation movement (Emerson & Hatton, 1996); the social movements of the 1960s in which minority groups in society campaigned for greater civic rights and challenged social attitude about minority groups (White, 2003); the social model of disability (Oliver, 1990; Union of Physical Impaired Against Segregation, 1976); the normalisation movement (Wolfensberger, 1983); and policy supporting the equal participation of people living with disability in community life. Examples of the latter include the New Zealand Disability Strategy, the Americans with Disabilities Act (ADA), and the Disability Discrimination Act (DDA) in the UK.

Despite these increased efforts to increase community inclusion for people living with disability, Barnes (2012) contended that more needs to be done and lamented that many policy and legislative measures introduced to address deprivations experienced by people living with disability “have had only a marginal impact on the everyday experience of disablement, and the majority of people living with disability remain the poorest in all societies” (p. 24).

In summary, the notions of community, and community inclusion, are complex and difficult to define. However there is generally consensus that community is a product of the interactions between people and their social and physical environments. Community inclusion broadly refers to having access to resources and the ability to participate in social roles in the community on an equal basis with other citizens. People living with disability have traditionally experienced limited community inclusion, and although initiatives over the last several decades have brought many welcome gains, more effort is required to realise the full community inclusion of people living with disability.

In this thesis, community is conceptualised based on participants' reports of what community meant to them. More information on this definition of community is provided in Chapter Four (see section 4.4.1).

2.2.3 Disability and community in New Zealand

As described in Chapter One (see section 1.5) the number of people living with disability in New Zealand is growing. Although the number of wheelchair users in New Zealand is unknown, it was reported in the 2013 New Zealand Disability Survey that 13% of the national population (551,466 people) identified as having a mobility impairment (Statistics New Zealand, 2014). Furthermore, New Zealand has an accelerating ageing population who are more likely to experience disability. People over the age of 65 years are estimated to be just over one quarter of the total population (26.7%) by 2063, further increasing the likelihood that the number of people identifying as living with disability will increase (Statistics New Zealand, 2013). On the balance of this evidence it is likely that people who use wheelchairs are becoming a larger subpopulation in New Zealand.

Disability in New Zealand post-earthquakes

In 2010 the Ministerial Committee on Disability Issues developed the Disability Action Plan (DAP), to help realise the New Zealand Disability Strategy and UNCRPD within New Zealand. In July 2011, the Ministerial Committee on Disability Issues decided that the DAP would focus on the Canterbury Recovery for the following eighteen months. Two priority areas to improve the lives of people living with disability in the medium to long-term recovery included: 1) the reconfiguration of supports and services, and 2) improving the accessibility of the built environment. In 2012 the progress report on the DAP renamed the reconfiguration of supports and services priority to *enable good lives* to better reflect the desired outcome. Two more priorities were also added: *support access to employment opportunities* so that jobseekers had opportunities to gain employment in the post-earthquake context, and *improving emergency preparedness* in which lessons could be learnt from the Canterbury earthquakes to improve the response for people living with disability in future emergency situations. These four priorities are summarised in Figure 2.2.

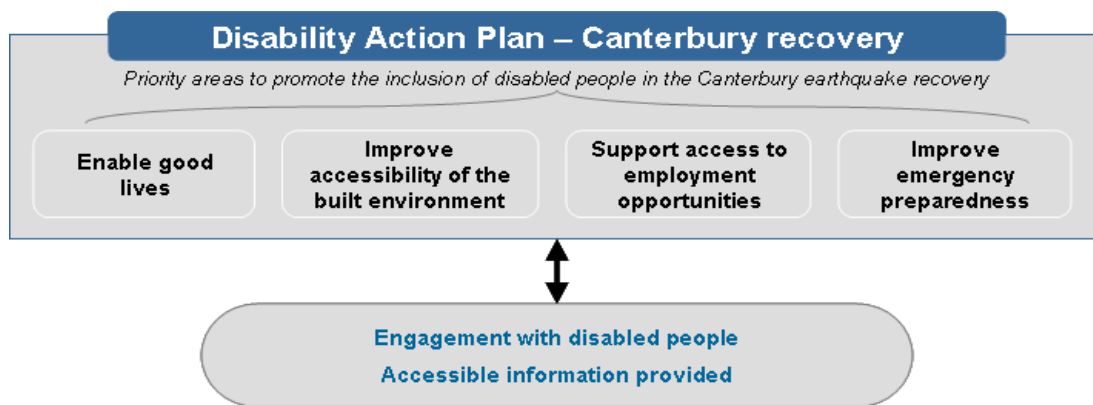


Figure 2.2. Disability Action Plan – Canterbury Recovery (Office of the Minister for Disability Issues, 2012).

Then in 2013 a revised DAP was created to cover the period between 2014-18. The 2013 DAP promoted the vision that all New Zealanders need to experience equal rights of citizenship at a national level by focusing on two areas: 1) person directed outcomes, and 2) shared results. Person directed outcomes included safety and autonomy, well-being, self-determination, community, and representation. The shared results section highlighted areas where government agencies would work together with disabled people's organisations to progress action, through increasing employment and economic opportunities, ensuring personal safety, transforming the disability support system, and promoting access in the community. Thirteen priorities were included within these four areas, including increasing the accessibility of the built environment and transport services for people living with disability, and promoting the inclusion of people living with disability in political and civic processes.

Due to the magnitude of the February 2011 earthquake, specific government legislation was passed to guide the rebuild and recovery. On 18th April 2011, the Government passed the Canterbury Earthquake Recovery Act (Canterbury Earthquake Recovery Authority, 2011). The Canterbury Earthquake Recovery Act had a number of purposes, the first being “to provide appropriate measures to ensure that greater Christchurch and the councils and their communities respond to, and recover from, the impacts of the Canterbury earthquakes” (Canterbury Earthquake Recovery Authority, 2011, p. 5). The Act provided for a new ministerial position, that

of the Minister of Earthquake Recovery. The Act also provided for the establishment of the Canterbury Earthquake Recovery Authority (CERA); whose mission was to coordinate the recovery on behalf of the Government. The chief executive of CERA reported directly to the Minister of Earthquake Recovery. The Act required a commitment to New Zealand's disability policy initiatives. Section 19 (2) d of the Canterbury Earthquake Recovery Act makes clear that the Minister of Earthquake Recovery "must have regard" to the NZDS (Canterbury Earthquake Recovery Authority, 2011, p. 13).

It is difficult to evaluate whether the policy initiatives outlined above have been implemented at a national level, and more specifically in Canterbury following the 2010/2011 earthquakes. However, several sources provide some insight. Firstly, the Office of the Minister of Disability Issues produced a progress report evaluating the implementation of the 2012 DAP (Office of the Minister of Disability Issues, 2012). The report outlined a number of priorities regarding the four areas described in Figure 2.2. One of these was that the Canterbury rebuild offered a once in a lifetime opportunity to create a truly accessible city that will not only benefit people living with disability, but also the aging population, and create a desirable place to visit. A second priority was to consult with people living with disability regarding the redesign of public transport and developing accessible homes. The progress report also outlined several initiatives focused on the fourth priority, improving the emergency preparedness of people living with disability. These include increased levels of psychosocial assistance through general practitioners and the Canterbury District Health Board, and a Ministry of Social Development-funded 0800 RELATE (735283) helpline. Further initiatives to improve emergency preparedness included greater communication and information sharing between health and disability services and Ministry of Civic Defence and Emergency Management.

In addition, the Human Rights Commission produced a report in 2013 monitoring human rights during the Canterbury earthquake recovery (Human Rights Commission, 2013). Regarding accessibility, the report recommended the local and central government ensure that accessibility and universal design were integrated into

regulatory frameworks. The report highlighted several positive findings surrounding issues of accessibility such as CERA partnering with Barrier Free New Zealand Trust⁴ to ensure anchor projects in the rebuild would be subject to accessibility audits. However, the report also highlighted some concerns, for example that a number of two and three level buildings had been constructed without lifts or the capacity to include them later.

Third, the Independent Monitoring Mechanism of the UNCRPD (a partnership between the Human Rights Commission, the Ombudsman, and the New Zealand Convention Coalition Monitoring Group) released its second report in December 2013. The report recommended that more work was required regarding the collecting and analysis of data relating to people living with disability, improving accessibility, building a people driven system, preventing violence and abuse, and increasing access to education. The report also identified specific concerns regarding proposed amendments to the Building Amendment Bill that could undermine current accessibility requirements when upgrading earthquake-prone buildings. These proposed amendments were a result of a recommendation in part two of the Canterbury Earthquakes Royal Commission's final report, that if acted upon would change the building code to such an extent that the revised version would run contrary to the aims of both the NZDS and the DAP. Section 112(1) of the current building code states that building consent authorities must not grant consents for the alteration of buildings unless satisfied that following the alteration there will be provision for access, facilities, and escape from fire for persons with disabilities. However recommendation number 98 in the Royal Commission's report suggested that section 112(1) should be:

“...amended to enable building consent authorities to issue building consents for strengthening works without requiring compliance with section

⁴ A charitable trust that aims to encourage, promote, and facilitate the creation of accessible and usable build environment by everyone in the community.

112(1)(a)(ii). The existing provision would continue to apply to building consents for other purposes” (p 14).

The justification was that the Canterbury Earthquakes Royal Commission stated they heard “evidence that section 112(1)(a)(ii) can operate as an impediment to building owners strengthening their buildings” (p. 14), and that there was a need to “strike an acceptable balance between cost and strengthening work, and the desirability of the latter actually being carried out” (p. 14). This illustrates the tension that can exist between the requirement for accessibility and the cost of its implementation.

Fourth, in 2015, the United Nations reviewed New Zealand’s implementation of the UNCRPD that New Zealand signed in 2007 (United Nations Committee on the Rights of Persons with Disabilities, 2014). Despite some positives, the review identified many areas of concern, including that people living with disability experience barriers to community inclusion, and that “persons with disabilities to some extent have no option than living in residential facilities for the elderly” (United Nations Committee on the Rights of Persons with Disabilities, 2014, p. 5). The committee recommended that more initiatives and services were required to enable people living with disability to exercise choice and control as to where they live.

In summary, the number of people living with disability in New Zealand is increasing, and like other developed countries, the rights of people living with disability to equality and non-discrimination is supported by a number of policy initiatives that advocate for the equal participation of people living with disability in society. However, like other Western countries, translating this policy into practice is challenging, and despite many positive developments, several reports indicate that the ideals set out in the policy have yet to be realised.

2.3 Interaction between disability and disaster recovery

In this section I explore research that has concentrated on the interaction between disability and disaster, beginning by considering the literature examining the disability and short-term disaster recovery, specifically focusing on earthquakes and wheelchair users. In this section I also explore the small body of research exploring the longer-term experiences of people living with disability following natural disasters, and the theory that disasters perpetuate pre-existing social inequalities

experienced by people living with disability. Finally, in this section I examine the research that has so far explored the experience of people living with disability in Canterbury following the 2010/2011 earthquakes.

2.3.1 Disability and short-term disaster recovery

A majority of literature has focused on the experience of people living with disability in the time period shortly following a disaster, for example, the preparedness and response capability of people living with disability prior to disasters.

Disability and earthquakes

Early literature regarding the intersection between people living with disability in relation to the specific hazard of earthquakes focused on the immediate consequences of the event. A foundational study in this field was conducted by Tierney, Petak, and Hahn (1988) who aimed to develop a classification of people who live with disability based on functional need, and relate the different functional categories to the earthquake related needs. Drawing on a variety of sources, including accounts from people who had experienced the 1983 Coalinga earthquake in California, Tierney et al. (1988) suggested that persons with mobility and visual impairments and were most likely to encounter challenges immediately following an earthquake, particularly when attempting to evacuate buildings. A major conclusion of this study was that the built environment, namely a lack of access and egress routes in buildings occupied by people with mobility impairments, exposed “such persons to a higher degree of involuntary risk than members of the nondisabled population” (p. 104).

Research into the acute phase following an earthquake also explored the association between individual level factors (such as wheelchair type and behavioural traits), and how people felt and responded during earthquakes (Rahimi, 1993, 1994). Rahimi (1993) surveyed 33 people with mobility impairments following the 1989 Loma Pieta earthquake in California, and reported that participants who remained in a passive state during the shaking were less likely to feel vulnerable than those participants who responded in a active manner, such as trying to leave the room. In addition, Rahimi (1994) conducted a simulation experiment in which wheelchair users (both manual and power) were asked to perform tasks in a room during manufactured shaking equivalent to that of a low (M_w 4.0) and high intensity earthquake (M_w 6.5).

Participants who used a power wheelchair performed tasks much slower, and had more trouble manoeuvring and carrying supplies, compared to those using a manual wheelchair. A consequence of focusing mitigation strategies at the individual level is the development of policy and planning surrounding the emergency evacuations being focused on the functional ability of individuals with disabilities, demanding individual responsibility and preparation to mitigate risk as opposed to removing barriers which create inaccessible built environments (Alexander & Sagamola, 2014; Christensen, Blair, & Holt, 2007; Christensen, Collins, Holt, & Phillips, 2006).

More recent research more has examining more broad social level barriers specific to wheelchair users were highlighted by Nakamura (2009), who considered the lessons learnt from how a group of people living with disability experienced the M_w 7.3 earthquake in Hashin, Japan in 1995 and the subsequent period. Nakamura (2009) reported that following the earthquake, wheelchair users faced great difficulty finding houses. Nearly all of the accessible housing stock was destroyed, and landlords were reluctant to rent to wheelchair users because they considered wheelchair users a liability in another emergency, and worried about the physical damage a wheelchair might cause to their houses.

Disability and other natural disasters

Disaster research that has explored the connection between people living with disability (including wheelchair users) and a variety of different hazard types suggests that people living with disability, and those with compromised health are disproportionately vulnerable during the short-term response phase following natural disasters.

It appears that people with mobility impairments can vary in levels of preparedness compared to people with no mobility impairments. Uscher-Pines et al. (2009) compared preparedness behaviours of households with and without members with special needs, defined as a person who required assistance in order to evacuate a house. Households with a special needs member were more likely to have packed a bag, located a shelter, and organised a place to meet. However, no significant differences were recorded regarding the purchasing of food and water, awareness of evacuation routes, or of having an emergency plan to guide evacuation. A similar

variation in disaster preparedness was also reported by McClure et al. (2011), surveyed 487 people with a SCI who used a wheelchair more than 40 hours a week to determine how many felt they could evacuate from various locations, and how many actually had an evacuation plan. A greater amount of participants felt confident they could evacuate from various locations (e.g. home, work, city/town), compared with those who *actually* had an evacuation plan from the same locations.

Other populations, such as those with poor health and/or having pre-existing medical conditions, have also been found to vary regarding their level of disaster preparedness. Bethel, Foreman, and Burke (2011) examined data from the Behavioural Risk Factor Surveillance System Survey, a random digit phone survey conducted by state health departments in the USA between 2006 and 2008 (N=37,303). Bethel et al. (2011) analysed data from six states that opted to include the general preparedness module and examined associations between health status, disability status, and chronic health status and disaster preparedness. Their research found that participants with fair/poor health status, a disability status, or three or more chronic diseases, were less likely to have preparedness items (such as food, water, flashlight, and radio) than their healthier counterparts, but were *more likely* to have a 3-day supply of medication. In a similar study, Eisenman et al. (2009) analysed data from the 2004 Public Health Response to Emergency Threats Survey, a random digit phone survey in the Los Angeles county USA, examining the association between health status and disaster preparedness. In a sample of 2207, Eisenman et al. (2009) reported that people with fair to poor health, and those with a serious mental illness were less likely than those with excellent health or no mental illness to have household disaster preparedness and emergency plans.

Further research exploring has highlighted the important role of social networks and accessible infrastructure in enabling survival during the time shortly following disaster (Barile, Fichten, Ferraro, & Judd, 2006; Rooney & White, 2007). Rooney and White (2007) surveyed 56 people with mobility impairments regarding their experiences of living through natural disasters in the USA. Three experiences that were helpful for survival included preplanning experiences (such as having food, water, medication, and evacuation plans); having social networks (such as friends and family who could provide housing and food); and first responders, and co-workers

(for example, helping people down the stairs at work). Obstacles which restricted participants shortly after the disaster included damaged infrastructure, such as power and transport, inaccessible shelters and no options for temporary housing. Similar environmental obstacles such as inaccessible shelters and a lack of attention paid to the needs and concerns of people living with disability were also reported by Barile et al. (2006), who interviewed 15 women with disabilities regarding their experience of an ice-storm in Montreal, Canada, in 1998. Participants in the Barile et al. (2006) study felt these environmental factors were greater barriers compared to their impairments.

Furthermore, there appears to be little evidence of collaboration with people living with disability in designing emergency planning, ensuring that disaster response plans are often designed for able-bodied people. For example, a further obstacle to short-term recovery identified by participants in the above study by Rooney and White (2007) was that emergency personnel had little knowledge of disability needs and options to address those needs. This ‘one size fits all’ approach creates emergency organisations who struggle to understand the extent or specific nature of the issues that people living with disability face (Fox et al., 2007; Rowland et al., 2007).

2.3.2 Disability and longer-term disaster recovery

There is less literature exploring the longer-term implications of disasters for disabled populations, and of efforts to rebuild inclusive communities post-disaster. However, there is a small but growing body of literature indicates that people living with disability can still experience barriers to community inclusion up to three years following the initial disaster.

Some indication regarding the barriers when returning to daily routines following a disaster can be gleaned from the above study by Rooney and White (2007) whose participants reported that difficulties in returning to everyday routines included addressing the trauma of the event, and the lack of mobility due to damaged ramps and infrastructure in the community and home. Participants also remarked how repairing their homes took a long time to be repaired after the disaster.

Evidence regarding the longer-term recovery for people living with disability can also be drawn from several studies that have investigated the experience of people living

with disability during the recovery phase ranging between six months to two years following Hurricane Katrina in the USA in 2005. Fox et al. (2010) interviewed 56 people who experience disability six months following Hurricane Katrina and reported that barriers to living independently were still present and included disruption to accessible housing, transport, employment, and communication channels. Similar barriers were identified in a larger sample of case managers and case management supervisors, who collectively provided services to over 2,000 people living with disability, between 20 and 24 months following Hurricane Katrina (Stough, Sharp, Decker, & Wilker, 2010). Using a grounded theory analysis, Stough et al. (2010) suggested that people living with disability experienced a complex and lengthy process of recovery following a disaster, and that barriers to recovery included locating permanent housing, a lack of transportation options, and challenges working through the disaster service system. Direct accounts from 31 people who live with disability provided further evidence that significant barriers, such as finding accessible housing, transportation, employment, and accessing services, delayed recovery two years following Hurricane Katrina (Stough et al., 2016). Stough et al. (2016) argued that while these barriers are often experienced by the general population, the disability status of participants enhanced the challenges experienced when negotiating the recovery process.

A further study which examined the direct accounts of people living with disability was conducted by Irshad, Mumtaz, and Levay (2012), who considered the longer-term gendered consequences of people who were rendered permanently paraplegic three years after the 2005 Pakistan earthquake. It appeared that support networks for women had been strong during the initial period after the earthquake, but that these networks had weakened in the three years that had passed. Men on the other hand experienced strong levels of support at all times since the earthquake. Women also experienced higher levels of emotional and financial isolation than their male counterparts. Irshad et al. (2012) suggested that these gendered inequalities highlight the impact of pre-existing, socially constructed hierarchies that influence a person's access to resources.

Taken together, the studies above support the argument that people living with disability can experience barriers to community inclusion of the three years following

a natural disaster. Furthermore, these barriers can manifest in such ways that are less related to the natural hazard and the functional impairment of an individual, and more related to how society responds to those hazards. For example, when society restricts opportunities due to the lack of resources and accessible infrastructure during disaster recovery (Stough et al., 2010; Stough et al., 2016), and also the intersection between disability, disaster recovery, and gender (Irshad et al., 2012).

These socially constructed barriers provide an alternative narrative to much research that has explored disability and disaster from the individual concept of disability outlined in section 2.2.1, such as the research examining the preparedness of people living with disability. Indeed, a growing body of literature is exploring how social conditions in post-disaster contexts influence the experience of people living with impairments.

2.3.3 A natural hazard or a social disaster?

How natural hazards manifest within their social ecologies, and the social construction of disasters and vulnerability is attracting increasing attention. An argument gaining traction is that structural disadvantage experienced by certain populations prior to a disaster, including people living with disability, can be magnified in post-disaster contexts (Fjord, 2007; Fjord & Manderson, 2009; Morrow, 1999; Paton & Johnson, 2001). The social vulnerability perspective emerged in the 1970s when O'Keefe, Westgate, and Wisner (1976) argued in the journal *Nature* that disasters result from the dynamic interaction between natural hazards and the societal response to that hazard, and that “without people there is no disaster” (O'Keefe et al., 1976, p. 566). Peek and Stough (2010) claimed specifically that disasters do not affect populations in a random and indiscriminate manner, instead a “person’s exposure to risk, ability to prepare for, respond to, and recover from disasters are determined via a combination of social, economic and political factors” (p.1260). Taking a social vulnerability perspective, existing inequalities are magnified during society’s response to a natural hazard. Those with the least access to social, economic and political resources prior to a natural hazard are more likely experience the greatest negative outcomes following a natural hazard, making recovery even more challenging (Fjord & Manderson, 2009; Peek & Stough, 2010).

Wisner, Blaikie, Cannon, and Davis (2003) proposed the ‘pressure and release (PAR) model’ as a possible explanation for how social forces can influence a person’s post-hazard experience (see Figure 2.3). The PAR model asserts that underlying root causes (e.g. distant, invisible, often taken for granted phenomena, such as political and economic ideologies) contribute to ‘dynamic pressures’ affecting certain groups, leading to ‘unsafe conditions’. Dynamic pressures were defined as processes that translate root causes to unsafe conditions, for example how ideologies manifest as specific policies or legislative regulations that might affect physical infrastructure or working conditions. Finally, unsafe conditions are the day-to-day outcomes of the dynamic pressures, e.g. availability of safe housing and work places, or provision of state support. When populations occupying these unsafe conditions combine spatially and temporally with natural hazards, they are considered vulnerable and at risk.

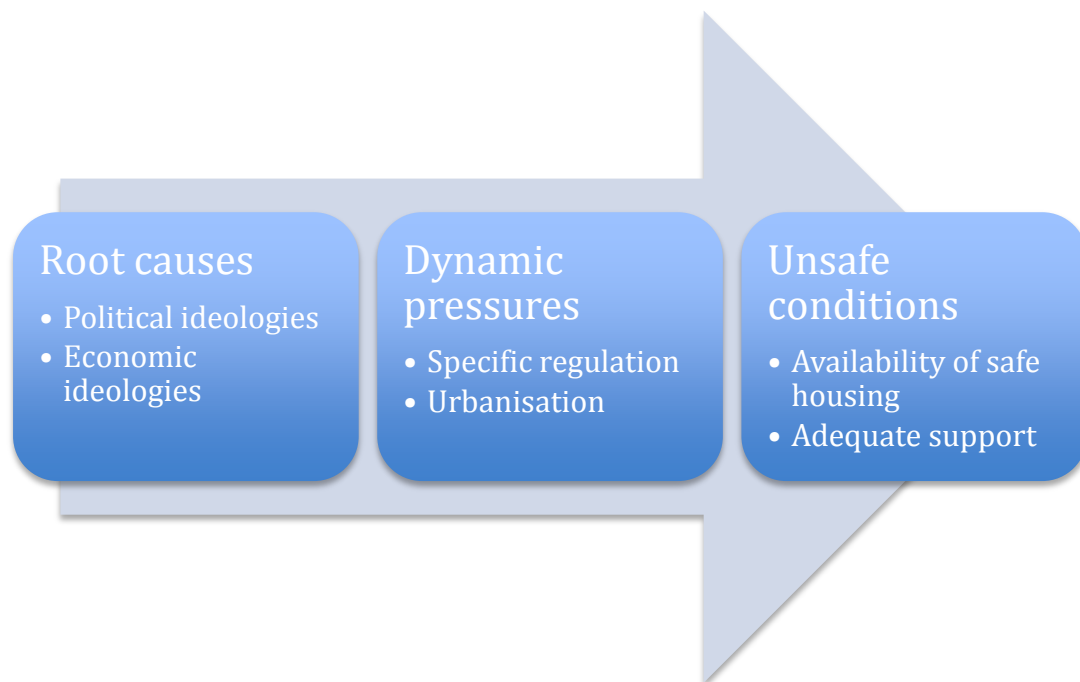


Figure 2.3. The Pressure and release model (PAR) (Winser, 2002).

The PAR model can be illustrated by examining how people living with disability are poorly represented in emergency planning. The root cause could be the ideology present for much of the twentieth century that frames disability as a deviation from normative ideals whereby people living with disability often experience less community integration, and consequently less access to civic resources (Hammell, 2006; Mitchell & Snyder, 2012).

The dynamic pressures could be that conventional disaster planning does not traditionally consult with, or prepare for, disabled populations (Fjord & Manderson, 2009). For example, Fox et al. (2007) interviewed managers of 30 counties that had experienced a disaster between 1999 and 2003 in the USA. Only 20% reported having specific plans in place to assist people living with disability, with 57% of managers not knowing how many people with mobility impairments lived in their jurisdiction. Two-thirds of counties with no disability guidelines had little intention of changing their policies to meet the needs of those with mobility impairments, citing barriers such as cost, limited staffing, and a lack of public education. Rowland et al. (2007) explored the scope of emergency training practices in three rural and three urban areas in the USA. An emergency administrator and a fire-fighter from each centre were interviewed. None of the agencies had emergency guidelines in place for working with people living with disability, instead suggesting that they deal with whatever comes their way. One fireman remarked “in an emergency situation... we’re going to do whatever we need to get them out” (p. 219). In terms of surveillance, none of the agencies held data of how many people in their area had mobility impairments.

Finally, the unsafe condition could be the potential lack of support from local authorities in the event of a natural hazard and response plans that lack information about the extent or specific nature of the issues that need to be addressed. In this scenario, people living with disability are vulnerable and at risk, arguably because of societal forces rather than individual attributes, a position highly congruent with the social model of disability.

This illustration of the PAR model, and how social forces can impact a person's post-disaster experience are congruent with both the social vulnerability perspective, and the social and cultural models of disability outlined earlier (see section 2.2.1). This example of the PAR model also demonstrates how the lack of quantifiable data regarding how many people living with disability reside in certain areas, underscores the importance of understanding basic epidemiological profiles of disability populations, and sub-populations – such as those who use wheelchairs – so that societies and agencies can understand and grapple with fundamental planning issues. However there are many challenges regarding how to define the parameters of people living with disability, ranging from whether people even identify as having a

disability, to the logistics of maintaining a registry (see section 2.4 regarding the methodological challenges researching disability).

2.3.4 The Canterbury earthquakes and disability

It appears that the experiences of people living with disability in Canterbury following the 2010/2011 earthquakes have been similar to those described in the international literature. People living with disability in Canterbury suggested the damaged infrastructure and buildings, inaccessible emergency shelters, and a lack of accessible showering and toileting facilities all created barriers to community inclusion in the months following the earthquakes (Phibbs et al., 2012). However, while many organisations were seen as lacking an understanding of the needs of people living with disability, the empathic responses of the community and emergency services were praised (Brereton, 2012; Phibbs et al., 2012).

Three sources provide insight into the issues experienced by the disabled community after the Christchurch earthquakes. The first was a two-day symposium held in Christchurch in May 2011, which included people living with disability, disability and health organisations, and government and non-government organisations. A report summarising the symposium was written by Ross Brereton (2012). The second initiative was a research report completed for the Ministry of Social Development (MSD) (Phibbs et al., 2012). This report aimed to inform both future guidelines and emergency planners as to the best way to support the disabled community in future disasters. A mixed methods design was employed that used qualitative interviews with people living with disability (n=25), and a quantitative survey (n=35, consisting of 25 people living with disability, 1 family member of a disabled person, 2 caregivers of people living with disability, and 7 disability agency representatives). The third was the CERA Wellbeing cross-sectional survey, administered every six months (Canterbury Earthquake Recovery Authority, 2012, 2013a, 2013b, 2014a, 2014b, 2015c) starting in October 2012 until September 2015, a total of seven times (n= 2,381; 2,438, 2,476, 2,511, 2,738, 2,550, 2,526). The survey was developed to gather data on the self-reported wellbeing of Canterbury residents, and also residents' perceptions of the recovery. The survey gathered data on people living with disability through a question asking respondents if they had a health condition or disability that has lasted over six months and restricts their everyday activities.

Phibbs et al. (2012) and Brereton (2012) both suggested that people living with disability were generally not prepared for a disaster before the 2010 September earthquake. However, Phibbs et al. (2012) and Brereton (2012) reported that people were slightly more prepared after September 2010. Specific ways people were prepared included: having a supply of water, food and medication; equipment (torch, candles, tin openers, batteries, rubbish bags etc.); a contingency plan; and copies of legal documents and cash. A general lack of emergency preparedness for people living with disability was not limited to the Canterbury earthquakes context. In 2014 Nicholls (2015) conduct a national survey of wheelchair via a snowball sampling approach through disability organisations and health service providers. From a sample of N=101, Nicholls (2015) reported that less than 30% of participants had an emergency plan, and less than 20% of participants were specifically prepared for their disability needs. Barriers to being prepared included needing assistance from others to prepare, a lack of disability information, and the lack of ability to stockpile medication or consumables (Nicholls, 2015).

Social support and community networks were a helpful resource for people living with disability. Brereton (2012) reported that people living with disability praised the efforts of emergency services, and work colleagues who demonstrated empathy and support following the earthquakes. Phibbs et al. (2012) also highlighted the importance of community response. Participants reported how neighbours checked on people, and friends helped with grocery shopping and jobs around the house. Participants in Phibbs et al. (2012) also mentioned the support they received from friends and family in other parts of New Zealand, for enabling disabled residents to leave Christchurch in the days after the February 2011 earthquake.

Damaged infrastructure had a significant impact on the daily lives of people living with disability. People living with disability at the Christchurch symposium reported that a lack of interim accommodation, toileting facilities, accessing necessary supplies, and inaccessible emergency stations were all problematic issues. Participants in the Phibbs et al. (2012) study reported that finding accessible housing was difficult after the earthquakes, with 63% reporting that they (or their clients) had to evacuate their homes. For those with mobility impairments who could drive, mobility was made more difficult due to roads being closed. For those who could not drive, the

closure of supermarkets and other businesses (especially in the eastern suburbs) meant that trips to shops and appointments required more organising, and were more expensive and time consuming. Certain buildings were also inaccessible due to lifts being out of order, leaving stairs as the only option, limiting the access for wheelchair users. Phibbs et al. (2012) reported that more consideration was needed when safety barriers and cordons were set up, and that disrupted public transport routes and infrastructure limited the mobility of people living with disability.

Organisational response for people living with disability was variable, with Phibbs et al. (2012) stating “because few people anticipated a disaster such as the February 2011 earthquake, institution responses were ad hoc and highly variable, with some disabled people receiving excellent support and others none at all” (p. 23). While people living with disability reported positive experiences with organisations that were used to dealing with people living with disability, communicating with welfare centres and larger government organisations was difficult and information about available and/or appropriate disability services was often ambiguous. In regard to welfare centres, both Brereton (2012) and Phibbs et al. (2012) reported that people living with disability had trouble accessing these centres. Concerns included accessing transport to the welfare centre, access into and within the centres, hygiene, attitudes, and having specialised equipment (beds and hoists) inside the centres. People living with disability also described communicating with larger government services was challenging. A lack of inter-agency communication, centralised service delivery, and lack of disability specific information made dealing with government organisations problematic (Phibbs et al., 2012). Brereton (2012) reported that there was generally a poor rate of consultation with people living with disability regarding emergency planning prior to the September 2010 earthquake, and that the needs of people living with disability were not well integrated into Ministry of Civil Disaster Emergency Management guidelines.

The CERA Wellbeing Surveys (Canterbury Earthquake Recovery Authority, 2012, 2013a, 2013b, 2014a, 2014b, 2015c) provided some insight into how people living with disability fared as Canterbury recovered following the earthquakes. In all seven administrations of the cross-sectional survey there were significant associations between respondents who identified as disabled and negative outcomes. For example,

those with a disability or health condition were among those who were less likely to rate life positively, more likely to say they experienced stress always or most of the time, and were more likely to score less than the overall Canterbury mean on the WHO-5 Wellbeing Index (Topp, Østergaard, Søndergaard, & Bech, 2015). Furthermore, respondents who identified as disabled in the CERA Wellbeing Surveys were also more likely to have less confidence and satisfaction in decisions made about the earthquake recovery by authorities including CERA and local councils.

In summary, in the second section of this chapter I have examined literature concerning the relationship between disability and disaster. A majority of literature in this area has focused on the initial period following a disaster, and people living with disability do not appear to have been any more prepared for disasters than non-disabled people. However, there is limited research exploring the longer-term experience of people living with disability following natural disasters, an area that requires more research. How the social environment impacts on a person's experience of recovery following a disaster is attracting more attention; structural disadvantage experienced by certain populations, including people living with disability, can be magnified in post-disaster contexts. The experience of people living with disability in Canterbury following the 2010/2011 earthquakes appeared to reflect the trends in international research. However, to my knowledge, no research exists that examines the experience of people living with disability in Canterbury over the longer-term recovery context.

2.4 Recruitment challenges researching disability

In the final section of this chapter I examine a particular yet fundamental methodological challenge in disability research: recruiting a representative sample for quantitative studies. People living with disability, including those using wheelchairs, rarely have a readily available sampling frame, leaving researchers with little option but to use recruitment methods that by default can exclude people living with disability and recruit non-representative samples. This context warrants the trial of alternative and novel recruitment methods.

Fundamental to good quality research, upon which statistical inferences are based, is that people of interest have a probabilistic and quantifiable (non-zero) chance being selected into a study (Rothman et al., 2008). This, in theory, ensures that a sample is

representative of the population from which the sample is drawn and that particular sub-groups of the target population are not over and under-represented (Coolican, 2004). Probability sampling, and having a representative sample, is essential for application of inferential statistical techniques that allow reliable, unbiased estimates of the study's target population providing greater confidence that results can be generalised to the wider population from which the sample was drawn (Aday & Cornelius, 2006; Rothman et al., 2008). In nonprobability sampling, the chance of any individual within the target population being included in the study cannot be empirically estimated, introducing a sampling bias. The extent of this sampling bias can be difficult to ascertain because the population parameters are unknown.

To employ probabilistic selection to recruit representative samples, most conventional epidemiological designs require the target population to be well defined, and that a valid and applicable sampling frame exists. A sampling frame is a list (or source) of everyone in a target population from which the sample will be drawn. Qualities of a good sampling frame include clear parameters regarding who is included and excluded, up to date information of new people who qualify and people who might cease to qualify, and reliable and up to date contact information (Aday & Cornelius, 2006; Coolican, 2004).

Recruitment methods typical of disability research, and indeed studies with wheelchair users, are usually nonprobability, convenience sampling approaches, such as circulating invitations via disability organisations or personal and participant networks, displaying public notices, and recruiting via fragmented databases (Edwards and McCluskey, 2010; Nary et al. 2012). Such nonprobability recruitment methods are also employed when recruiting wheelchair users in disaster contexts, such as recruitment using databases where the sampling frame may not incorporate the entire target population (McClure et al., 2011), and chain-referral approaches (Nicholls, 2015).

In disability research, the reliance on convenience sampling approaches means that those individuals that have a zero probability of being selected (i.e. those individuals not connected through the recruitment approaches outlined above) are not heard; the very reasons they are not 'connected' may be related to experiences and attitudes, and/or a demographic profile that differ from those who are connected through such

traditional recruitment approaches. Indeed, Shakespeare (2014) has voiced concerns as to what extent those who are members of disability organisations are representative of the disability population as a whole. For example, it is plausible that older people may be more likely to join disability organisations, biasing current recruitment methods towards an older age bracket.

Registries can offer a potential mechanism for probabilistic selection, possibly reaching those people who cannot be contacted through the traditional recruitment approaches outlined above. However registries (either based on impairment such as SCI, or based on functional needs such as wheelchair use), which could provide a sampling frame, are relatively uncommon (Fitzgerald et al., 2007; Smaill, Schluter, Barnett, & Keeling, 2016; Smaill, 2015). The general lack of registries coincides with a time when people living with disability, including wheelchair users, are increasing in absolute and relative terms (see section 2.2.3). Of great encouragement, New Zealand has very recently implemented a SCI registry, which was not available during my recruitment period.

The difficulty in recruiting representative samples, combined with the increasing prevalence of wheelchair users, creates a context in which innovative sampling strategies that can potentially deliver probabilistically samples warrant exploration. As Andresen (2011) contends:

The challenges of disability research that confront epidemiology also serves as a substantial impetus to expand methodological innovation, extend traditional epidemiological thinking, and learn from our knowledgeable communities (p. 35).

A new and emerging sampling approach that has not been used to sample wheelchair users is Respondent Driven Sampling (RDS). RDS is a chain referral type approach that can provide unbiased population-based estimates if certain assumptions are met. Traditional chain-referral sampling approaches are often inherently biased to the initial participants, and this bias may compound as the waves continue. RDS was developed to counter these biases, employing specific data collection and statistical analysis methods which enable valid population-based estimates (Heckathorn, 1997; Volz & Heckathorn, 2008; White et al., 2015).

RDS requires that a number of conditions be met in order to be effective: that participants are assumed to recruit randomly from their networks, that recruitment chains are traced using recruitment codes, and that participants provide an estimate of their network size (the number of people a person knows in the target population). This information then “makes it possible to compute how many waves must be completed before the sample approximates the equilibrium distribution, and thereby becomes independent of its starting point” (Heckathorn, 1997, p. 197). RDS has become an increasingly used sampling approach over the last two decades with over 120 RDS studies reported in more than 20 countries with over 30,000 participants (Malekinejad et al., 2008) and in participant groups such as those with greater risk of HIV, including injecting drug users (Young, Rudolph, Quillen, & Havens, 2014) and sex workers (Simic, Johnston, et al., 2006). Despite wider adoption of RDS, and its successful application in many topic areas, methodological concerns have been raised. For example, the assumption that participants recruit randomly has been challenged (Philips, Kuhns, Garofalo, & Mustanski, 2014; Young et al., 2014).

The lack of an available sampling frame for the target population of my research inhibited the ability to recruit a representative sample, and ability to generalise the findings. This challenge motivated the secondary aim of this thesis: to trial RDS in the quantitative phase in an effort to address the challenge of recruiting a representative sample in a population of wheelchair users. Details surrounding the administration and implications of using RDS are outlined in Chapter Five and Chapter Six respectively.

2.5 Summary

The first section of this chapter drew on literature exploring the nature of disability and community, and how these two concepts have been framed in recent decades. Broadly, disability has been reframed from being an individual attribute, to being a consequence of wider structural disadvantage. The second section considered the impact of natural disasters on disabled populations. At both the individual and organisational level, research suggests people living with disability face greater challenges in accessing resources following a natural disaster. A lack of physical access, equipment, information, and education are posited as contributing reasons. The challenges that face people living with disability after a disaster reflect a wider

inability of society to afford equal access and opportunities to people living with disability in the absence of a disaster; a post-disaster context in which resources and regular social routines are compromised merely magnifies this imbalance.

In this chapter the particular challenge surrounding recruiting representative samples in quantitative disability research has also been considered. The lack of recruitment methods which offer probability sampling, and the absence of the sampling frame for my target population, has motivated the decision to try a novel sampling approach, RDS.

Finally, this chapter has attempted to illustrate the gaps in the literature surrounding how people who live disability, in particular those who use wheelchairs, experience community inclusion in the longer-term recovery following disaster. There is a large body of literature which examines how people who use wheelchairs experience the period shortly after a disaster, and growing body of research examining recovery up to three years following a disaster. However, there appears to be no research which has which has combined a qualitative and quantitative component to investigate the experience of community inclusion for people who use wheelchairs four years following a disaster. The paucity of research addressing this issue inspired the question and design of the research described in this thesis.

2.6 The research question

Researchers are becoming increasingly encouraged to be cognizant of the philosophical, methodological, and practical methods used to address their research questions (Dures, Rumsey, Morris, & Gleeson, 2010; Mertens, 2007). Researchers must explain the rationale for their methodological position, and why they believe it is an appropriate position for the research question. Once the research question has been determined, then an appropriate way to answer that question can be explored. As stated at the end of Chapter One, the research question that this thesis aimed to explore was:

How have one section of the disability community – people who use wheelchairs –experienced community inclusion over the four years following the earthquakes in 2010/2011 in Canterbury New Zealand?

Specific aims of this study included:

1. To understand what a small sample of wheelchair users perceive to be the individual and social determinants of inclusion and participation in the Canterbury community in the four years post-earthquake.
2. To quantify and compare the findings of this Phase One with a larger sample of individuals who use wheelchairs at different time points using a descriptive epidemiological approach, and to investigate associations between Phase One findings and level of exposure to the 2010/2011 earthquakes.
3. To test a novel sampling approach, RDS, which had the potential to enable the calculation of unbiased population-based estimates that could be generalised to the target population.
4. To consider these findings within the context of the disability legislation in New Zealand and produce information which enables local and central government organisations to facilitate community inclusion for people who use wheelchairs during the longer-term recovery phase following a natural disaster.

The research question and aims were influenced by a number of factors, namely that there is very little research that has explored the community inclusion experience of people who use wheelchairs in the longer-term recovery after a natural disaster. Furthermore, New Zealand has several pieces of legislation advocating for provision of equal opportunities for people living with disability in all aspects on community life in New Zealand (see section 2.2.3). Finally, central government in New Zealand is being increasingly advised to formulate and implement policy decisions based on research-informed evidence (Gluckman, 2013). Following the establishing of the research question and aims, the next step was to explore the most suitable methodology and methods to offer a robust understanding of phenomena. For this thesis it was decided that the research question and aims were best examined using a mixed methods design. The following chapter describes the justification for this design.

Chapter Three: Methodology and Methods

3.1 Introduction

This chapter outlines the methodology and methods used in this thesis, and provides a rationale as to why a mixed methods approach, in particular an exploratory sequential design, was considered appropriate. This chapter charts the theoretical underpinnings of such a design, drawing on the pragmatism paradigm and values of inclusion and equality for people living with disability. This chapter does not describe the nuances of the specific methods used; a detailed description of the component methods used in each phase is presented in Chapters Four and Five respectively. Community consultation, ethical considerations and funding acknowledgements are also described at the end of this chapter.

3.2 Researcher position

The notion of the detached, objective researcher has been challenged in recent decades, substituted by the view that researchers play an active role in shaping their research process, and in turn are shaped by their research (Braun & Clarke, 2006). Rather than being a source of contamination the assumptions, values, and position of a researcher should instead be made explicit: thus being a resource for the reader and promoting rigorous and transparent research. To this end, in this section I describe my personal and academic experience and how this has influenced my assumptions regarding disability studies, disability research, and disability advocacy. I also specifically discuss my position as an insider researcher, in that I share a number of experiences with participants.

As a reflexive researcher, I acknowledge that it is inevitable that my experience of disability and academic background influence my research. My personal experience of disability began in 2005 when I sustained a SCI, which resulted in complete paralysis from my shoulders down, and limited movement in my arms. I have used a power wheelchair for mobility since my injury. I live in a country with a state funded insurance scheme so that almost all of my equipment and medical needs are funded and supplied.

My academic interests and training also influence my assumptions surrounding disability. At tertiary level my undergraduate degree in psychology included papers in

sociology, rehabilitation, and disability studies. Combined with my personal experience of disability, my undergraduate degree sparked my interest in disability studies and rehabilitation. These interests led me to complete a Masters of Health Science (Rehabilitation). My Master's thesis was an in-depth qualitative study that explored how people with tetraplegia as a result of spinal cord injury (SCI) experienced rehabilitation (Bourke, Hay-Smith, Snell, & DeJong, 2015).

Despite these privileges I have also experienced what I term 'disability'. At a physical level, I experience a great deal of pain, fatigue, and must remain eternally vigilant regarding the management of my health. For example, I have experienced compromised skin integrity in the past, which required a great deal of time on bed rest. At a social level I have experienced many instances of discrimination and reduced opportunities due to restrictive physical and social environments, and belittling cultural attitudes within the community, reflecting the 'personal tragedy' view of disability (see section 2.2.1, the individual model of disability). Conversely, I have experienced many instances where accessible environments, and supportive social networks, have enabled me to enjoy many of the opportunities available to persons without a high level of physical paralysis and 'disability'.

The sum of my experiences has led me to hold a certain view on how to conceptualise the complexity of disability. I feel that the social model of disability has been fundamental to challenging the individualistic and personal tragedy worldview of disability, and succeeded in highlighting how social, economic, and political factors can cause and sustain disablement (Barnes, 2012; Barnes & Mercer, 2010; Oliver, 1990). Building on this foundation, I also feel that more recent arguments 'to bring the body back' into disability studies add to our understanding of disability. For example the functional and psycho-emotive aspects of physical and cognitive impairment play an important role, and must be acknowledged as contributing to the experience of disability (Morris, 1990; Thomas, 2007). I do not feel that it is productive to reduce the determinants of disability to one phenomenon whether it is physical or social. Furthermore, I feel that arguments highlighting the role that discourse and culture play in contributing to disability are also valid. I endorse the sentiments of Meekosha and Shuttleworth who said that "the struggle for social

justice continues: one that is not simply social, economic and political, but also psychological, cultural, and discursive” (Meekosha & Shuttleworth, 2009, p. 50).

My experience has also led me to reflect on my views regarding the relationship between disability research and disability advocacy. Disability advocacy is typically characterised through services and/or advocates partnering with people living with disability to provide practical support to fight discrimination and uphold human rights. Alternatively, researchers have typically controlled disability research, including the topic, design, and process; with little to no input from people living with disability (Barnes & Mercer, 1997). In Mike Oliver’s seminal 1992 paper regarding the social relations of research production, he argued that because disability research had alienated people living with disability from the research process, disability research had made no contribution to addressing the social oppression experienced by people living with disability and had had little influence on policy (Oliver, 1992).

I contend that, two decades on from Oliver’s paper, disability research can be conducted in such a way that aligns with the goal of disability advocacy; namely, the positive transformation of the lives for people living with disability. Research which is transparent and reflective regarding its foundations, engages in a rigorous and critical analysis of the data, and engages in an accessible and pragmatic dissemination plan, can indeed complement, and rightfully engage in, disability advocacy in an ethical and practically orientated manner (Sullivan, 2009). A further step towards achieving transformative disability research is to prioritise the direct accounts of people living with disability. Giving voice to people living with disability is necessary to further our understanding of the nuanced manifestation of disability. Such research must be considered within the social, political, and cultural context in which it is conducted, while also acknowledging the agency of people experiencing disability (Watson, 2012).

Such research can seek to achieve what Stone and Priestley (1996) argued is the key obligation of disability researchers: to achieve the twin goals of academic rigour and political action. The strength and value of such disability research lies in its ability to contribute to what Mmatli (2009) named “evidence-based advocacy” (p. 21). Such an argument is implicitly connected to the paradigms which underpinned the research of this thesis; pragmatism and the transformative paradigms (see section 3.4 below).

The final consideration in this section is how my experience specifically influenced my work on the research in this thesis. For my research, I can be considered an ‘insider researcher’ in that I share certain experiences with the participants regarding the topic of investigation in my research, for example, I use a wheelchair, reside in Christchurch, and experienced several of the 2010/2011 earthquakes (Le Gallais, 2008). Of course there are a wide variety of influences on identity and experience, and the shared experience of using a wheelchair may sometimes only lead to a small degree of shared understanding. However, this insider status can have benefits, such as the potential for increased rapport with participants, increased ability to empathise with their experience, and potentially a more nuanced interpretation of the data (Le Gallais, 2008). Insider research can also present potential challenges. For example during my time using a wheelchair I have inevitably developed certain assumptions regarding life as a wheelchair user, and this could influence the way I collect, view, and analyse data.

My response was to acknowledge and be reflective of my subjective position, in particular how my insider position might influence the research. During my research I kept a research journal throughout the study, a practice strongly encouraged for qualitative researchers and those reflecting on their position as an insider researcher (Braun & Clarke, 2013; Le Gallais, 2008). My journal included reference to the research journey, and also autobiographical notes. This journal allowed me to reflect and revisit my thoughts, actions and how they influenced my interpretations of the data. This fits within the approach of thematic analysis, which acknowledges the active role of the researcher and that ‘understanding and representing participants’ experiences requires interpretative activity: it is informed by our own assumptions, values, and commitments’ (Braun & Clarke, 2013, p. 285). As well as keeping a research journal, I also had numerous discussions with my supervisors and colleagues.

To summarise, in this section I have discussed how my background and disability experience have combined to influence my values and assumptions surrounding disability, research, and advocacy. I have also discussed my role as an insider researcher in that I share certain experiences with my participants. The next section describes the foundations underpinning the methodological position of this thesis. This thesis drew on a pragmatic approach to inform the research design, and was also

influenced by many values inherent in the transformative and emancipatory approaches.

3.3 Mixed methods methodology

Research in the social sciences has been traditionally conducted using one of two approaches: quantitative approaches, which collect numerical data that are subject to statistical analyses to describe and observe relationships between variables (e.g. an experiment or survey); or qualitative approaches, which seek to interpret in-depth details and meaning that people attribute to a specific experience (e.g. data collection via a semi-structured interview). However a third approach, the concept of mixing quantitative and qualitative methods in a single study, has experienced an increased use as a distinctive type of research methodology over the last two decades (Biddle & Schafft, 2015; Creswell & Plano Clark, 2011). Indeed, mixed methods research has even been termed the “third methodological movement” (Tashakkori & Teddie, 2003, p. ix).

The generally agreed definition of a mixed methods research is a study that involves the collection and analysis of both a qualitative strand and a quantitative strand in the context of a single study, and that the two strands are integrated at some point during the study (Creswell and Plano, 2011). The main argument in favour of mixing methods is that it can provide a richer analysis of a research question than just one method can alone. For example, qualitative and quantitative approaches can be used to address different parts of a research problem, complementing each other to provide a comprehensive understanding (Woolley, 2009). Qualitative data such as words, pictures, or narrative can add meaning to numbers. Similarly, numbers can add precision to narrative and words (Johnson & Onwuegbuzie, 2004).

It is important for researchers to provide a clear and justified rationale for conducting any research, including mixed methods research. There have been a number of reasons and justifications for deciding to combine two methods in one study. Greene, Caracelli, and Graham (1989) conducted a seminal paper exploring the reasons for conducting a mixed methods study, analysing 57 empirical mixed method evaluation studies and identified five key purposes for conducting a mixed methods study. These included triangulation, complementarity, development, initiation, and expansion. More recently Bryman (2006) reviewed 232 mixed methods studies and suggested

that the most prominent rationale for mixing qualitative and quantitative methods was enhancement, which Bryman argued corresponds to complementarity. Complementarity refers to the “elaboration, enhancement, illustration, clarification, of the results from one method with the results from the other method” (Greene et al., 1989, p. 259).

Despite much enthusiasm for mixed methods research, Giddings (2006) offers some words of caution. Giddings’s (2006) main concern is that an uncritical assumption that mixing qualitative and quantitative methods which promises “the best of both worlds” (p. 195) can, in fact, marginalise the diversity within qualitative and quantitative methods (primarily for the former), thereby creating research designs that can unconsciously favour the post-positivist position (Giddings & Grant, 2007). To counter this possibility, Giddings (2006) argues that to conduct rigorous and thorough mixed methods research requires careful and considered planning. In particular this planning should acknowledge the underlying methodology, the theoretical assumptions and underpinnings informing a research design, and the methods: the practical means used to reach outcomes (Denzin & Lincoln, 2005).

The fundamental rationale for using mixed methods in this thesis drew on the idea of development and complementarity. Findings from the qualitative phase informed the *development* of an instrument administered in the second, quantitative phase to measure the prevalence and relationships of those constructs within a larger representative sample. Then, findings from the second quantitative phase helped to further *enhance and complement* the findings of the qualitative phase. I felt that having findings from the two methods would complement and build upon one another to provide a deeper, enhanced understanding of wheelchair users’ experience of community inclusion, more so than conducting a qualitative or quantitative investigation in isolation (Creswell & Plano Clark, 2011). Furthermore, the state of knowledge on this topic (which is scant) also lends itself to an approach where an exploratory, qualitative phase is conducted first.

3.4 Theoretical assumptions

Despite its growing use, mixed methods research is sometimes challenged as being incompatible as qualitative and quantitative approaches are born from different paradigms that have separate ontological and epistemological assumptions (Sale,

Lohfeld, & Brazil, 2002). However, there is an increasing acceptance that different methods can be used in a single study; researchers need to be explicit in describing which paradigms were used to help frame the philosophical and theoretical assumptions informing their research (Dures et al., 2010; Shannon-Walker, 2015). By describing the ways in which paradigm(s) are used within a research project, readers can have a much better understanding of the foundations and influences on the research. My research study drew on concepts espoused by the pragmatism paradigm, as well as being underpinned by the values of emancipation and social justice. These positions and their application in the thesis are now described.

Pragmatism has been promoted as an ideal philosophical foundation for mixed methods research as it acknowledges that multiple forms of knowledge can exist. Pragmatism has focused on developing workable solutions to many of the philosophical dualisms surrounding issues of metaphysics, such as the nature of truth and reality (Johnson & Onwuegbuzie, 2004). In social science research, this often manifests in the dualism between the realism underpinning quantitative approaches (a single, external reality only understood through objective enquiry) and the constructionist ideology underpinning qualitative approaches (that multiple realities exist based on subjective interpretations of differing contexts) (Cornish & Gillespie, 2009; Creswell & Plano Clark, 2011; Johnson & Onwuegbuzie, 2004). Pragmatism rejects such dualisms and, instead of being in competition with each other, different forms of knowledge are seen to serve different purposes (Creswell & Plano Clark, 2011). In determining a purpose, pragmatists hold that research questions should address the concrete problems people face in everyday life in order to provide positive social action (Cornish & Gillespie, 2009). From a pragmatist perspective, knowledge is constructed, viewed, and valued within the context of action. Pragmatism moves the question away from ‘does this knowledge reflect reality’ to ‘does this knowledge serve our purposes?’ (Cornish & Gillespie, 2009, p. 802).

The practical application of pragmatism to mixed methods research can be visualised through using an abductive-intersubjective-transferable framework (Evans, Coon, & Ume, 2011; Morgan, 2007; Shannon-Walker, 2015). In this framework “reasoning moves back and forth between induction/deduction and subjectivity/objectivity... and with regard to transferability, how knowledge created might be used in a new setting”

(Evans et al., 2011, p. 277). This thesis used such a framework: abduction was required when moving between the rich data-led inductive reasoning from the qualitative phase, the findings of which were then evaluated for their predictive ability in the quantitative phase. I also felt inter-subjectivity was appropriate to acknowledge the role that my perceptions played in the interpretation of the themes in Phase One, alongside the comparative objectivity required concerning the quantitative research in Phase Two. Finally, the pragmatic notion of transferability was considered relevant to help navigate the integration of both datasets, where interpretations might move back and forth between specific results and more general implications, and how the findings of research might be extrapolated to other settings (Morgan, 2007; Polit & Beck, 2010).

While pragmatism can provide a foundation for focusing on ‘what works’, this practicality can be at the expense of addressing the role that ethics and values play in guiding research decisions. Biddle and Schafft (2015) contend that there is a “problem of axiological underspecification in the practice of pragmatic mixed methods” (p. 331), and suggested that pragmatic mixed methods research can learn from the transformative paradigm. The transformative paradigm places the values, or axiological assumptions, such as social justice and human rights as fundamental in informing research decisions (Mertens, 2015). The values inherent in the transformative paradigm parallel closely with the values of emancipatory research, founded on the social model of disability, and focusing on exposing and changing disabling structures in society. Such disabling structures included addressing the unequal power relations that have always been a major concern within disability research, specifically, who controlled and benefited from disability research – the researchers, or people living with disability (Barnes & Mercer, 2003, 2010; Oliver, 1992).

The values informing the present study were such that an explicit effort was made to conduct research that was considered ethical, inclusive, and as having practical outcomes for people living with disability. For example, the values of social justice and inclusion were central when framing my research project. This was realised in two ways. First, the concepts of social justice and equality are values I hold (see 3.5 research position). Second, to conduct ethical disability research, researchers need to

consider the position of participants within the research process and whether the voices of people who have a greater probability of discrimination and oppression are included into the research process (Mertens, 2007; Sullivan, 2009). To this end, the research proposal for this thesis was submitted for consultation with the disability community (see section 3.6 and appendix B), and the initial qualitative phase of this thesis focused on hearing the voice of participants through asking for their views, perceptions, and experiences regarding community inclusion in an open-ended manner. Furthermore, the findings of this study were presented to local disability organisations for feedback as the findings became available. Finally, in an effort to inform social awareness and change, a dissemination plan (see section 6.3.1) was developed in order to ensure the findings will be translated to all relevant local council and government organisations with the ultimate goal to highlight the degree to which participants felt they were (or were not) included in the Canterbury community recovery.

In sum, in this section I explicitly discussed the foundations and reasons underpinning the methodological position of this thesis. My thesis drew on a pragmatic approach to inform the research design, and was also influenced by values inherent in the transformative and emancipatory approaches. The next section of this chapter focuses on the specific research design.

3.5 Design of the thesis research

The specific mixed methods design used in this thesis was called an exploratory sequential design, which begins with a qualitative phase, followed by a quantitative phase. In the first phase, qualitative data are collected and analysed for key themes and patterns to provide an understanding of the potential constructs within a phenomenon. Creswell and Plano Clark (2011) suggest an exploratory sequential design is best suited to contexts where there has been little or no research conducted, to provide insight, and where exploration of a phenomena is required because there is no instrument to measure the topic in question, and/or the constructs, or variables, are unknown. This aligned with the research topic of this thesis as there appeared to be no instrument currently available to quantify the longer-term experience of people who use wheelchairs following a natural disaster, and there appeared to be no research investigating first-hand accounts of people who use wheelchairs (or indeed other

disability communities) regarding their experience of community inclusion over the longer-term as communities recover following major natural disasters. As such, the qualitative investigation conducted in Phase One exploring the context-specific experience of wheelchair users in Canterbury was considered necessary to gain insights to inform development of an instrument to measure community inclusion for wheelchair users for Phase Two. Phase Two was necessary to develop and enhance the findings of Phase One through providing an opportunity to examine the prevalence of the themes identified during the thematic analysis conducted in Phase One and the relationships between important variables.

Important considerations when designing a mixed methods study include the sequence of the qualitative and quantitative phases (Johnson & Onwuegbuzie, 2004). An exploratory sequential mixed methods design begins with an initial qualitative phase and the findings inform the development of a second, quantitative phase. In my thesis, understanding wheelchair users' experience of community inclusion in the first instance was best explored through interviewing a small sample of individuals who use wheelchairs in Christchurch. A qualitative thematic analysis of these interviews focused on eliciting rich, detailed information in order to interpret important constructs. The findings of this analysis were used to develop a survey instrument, which was designed to measure the prevalence of those constructs in a larger sample (see Figure 3.1). This sequence can be linked back to the concept of enhancement described above in section 3.3.

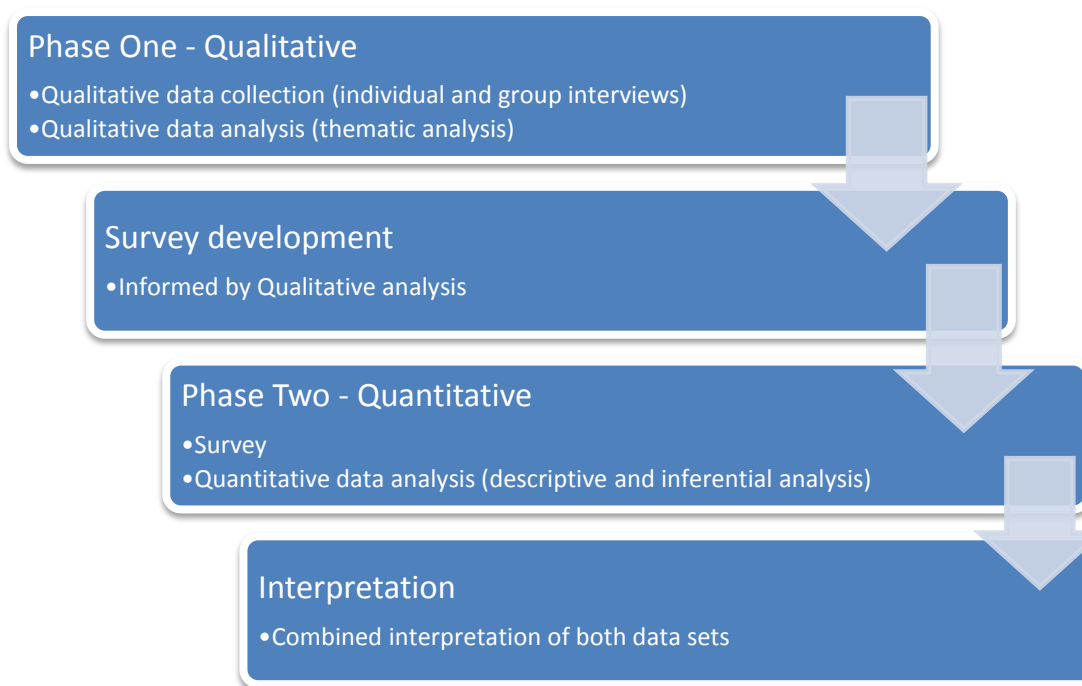


Figure 3.1. The exploratory sequential mixed methods design for my research.

Describing how a mixed methods design matches the stated research aims can improve the reporting of mixed methods research (Heyvaert, Hannes, Maes, & Onghena, 2013). The specific ways in which an exploratory sequential design related to the aims of my thesis are summarised below. Both phases of the research were granted equal priority, based on the rationale that while independently they addressed specific research objectives, both were integral to realising the overall research question.

3.5.1 Qualitative Phase

The initial qualitative phase was directly related to the first aim outlined in Chapter One:

To understand what a small sample of wheelchair users perceive to be the individual and social determinants of inclusion and participation in the Canterbury community in the four years post-earthquake.

A qualitative approach was considered appropriate for this specific aim due to the newness of the research topic. Exploration was required to better understand how a small sample of wheelchair users interpreted their experiences and perspectives of

community inclusion following the earthquakes. Braun and Clarke (2013) suggest that qualitative research treats context as being very important, and that ‘experiential qualitative research validates the meanings, views, perspectives, and experiences expressed in the data’ (p. 21). The first aim of my research was indeed very focused on understanding the participants’ perspectives and experiences of community inclusion following the earthquakes. It was envisioned that a qualitative approach would provide a thick description of their experiences, in which a deeper understanding of the phenomena might be achieved through the open ended and exploratory nature of the interviews in which unanticipated ideas (for the researcher) might be expressed.

3.5.2 Quantitative Phase

The second, quantitative phase was designed to address the second aim:

To quantify and compare the findings of this Phase One with a larger sample of individuals who use wheelchairs using a descriptive epidemiological approach: and to investigate associations between Phase One findings and level of exposure to the 2010/2011 earthquakes.

A quantitative approach was considered appropriate for the second aim of my thesis. Johnson and Onwuegbuzie (2004) suggested that strengths of quantitative approaches include the testing and validating of constructs that propose to explain why certain phenomena may have occurred, providing precise numerical data that can allow for quantitative predictions such as the prevalence and interrelations between certain variables, and can provide the capacity to conduct group comparisons. Having confidence that statistical inference might reliably provide population-based estimates to generalised to the target population was a key reason for the methodological aim of my thesis: to test the use of RDS due to the lack of a sampling frame for the target population in the quantitative phase.

These strengths were considered applicable to the quantitative phase of my thesis. For example, operationalising the findings of Phase One into the survey used in Phase Two provided a means of understanding the prevalence of the findings identified in Phase One, and potential interrelations between the variables identified in Phase One

in a larger sample of wheelchair users. Also, data from the survey used in Phase Two provided the potential to conduct comparisons with data from other studies.

The integration of the qualitative and quantitative phases then addressed the third and fourth aims outlined in Chapter One:

To consider these findings within the context of the disability legislation in New Zealand

To produce information which enables local and central government organisations to understand important factors associated with the inclusion of people who use wheelchairs in community rebuilding following a natural disaster.

In sum, the use of mixed methods methodology was chosen because it was felt that it would provide a more complex understanding of the research aims than one method alone would have. In particular, an exploratory sequential mixed methods design was considered the most appropriate research design due to the lack of an instrument and, indeed, research that could have provided insight into the variables surrounding the phenomena of wheelchair users' experience of community integration in the years following an earthquake. An exploratory sequential mixed methods design was considered the most constructive approach to produce a robust and deep understanding of this phenomena.

3.5.3 How datasets were integrated

An important factor in the design of mixed methods studies is describing how the two phases are integrated (O'Cathain, Murphy, & Nicholl, 2010). Integration is the point at which the qualitative and quantitative components of a study interact and are mixed (Creswell & Plano Clark, 2011; O'Cathain et al., 2010). Without a concerted effort to integrate and interpret both datasets, the knowledge produced essentially reflects a qualitative and quantitative study conducted on their own. As a result, a fundamental purpose of conducting mixed methods research, to produce findings greater than the sum of the parts, is not realised (O'Cathain et al., 2010). Describing the points at which the different components of a study intersect can improve opportunities to assess the appropriateness of the study design for the research question. Indeed, the

rigour of a mixed methods study can be increased through clearly identifying *a priori* “where, how, and why data intersect” (Strudsholm, Meadows, Vollman, Thurston, & Henderson, 2016, p. 2).

The two phases of my research were integrated at two points. The first was when the data from Phase One informed the development of the survey administered in Phase Two: the specifics of this process are described in detail in Chapter Five (see section 5.3). Integration also occurred when both data sets were subject to a combined interpretation in Chapter Six (see section 6.2). The integration of datasets in Chapter Six occurred using a triangulation protocol (O'Cathain et al., 2010). In mixed methods research, triangulation is used to assess how findings from each phase agree, complement, or vary from each other, so that a more nuanced understanding of the phenomena may be interpreted. This assessment occurs whilst acknowledging that qualitative and quantitative methods explore a topic from a different perspective (Woolley, 2009).

3.6 Cultural and community consultation

A University of Canterbury Māori Consultation form was submitted to the Māori research consultant at the University of Canterbury for both phases of the research. A response regarding Phase One was not received due to transitioning of the Māori research consultant at the time, however a response was received regarding Phase Two (see Appendix A). A key suggestion was that I give careful thought to how I might share the findings of my research to ensure they are accessible to Māori who are interested, and potentially affected by the findings. To address this I will ensure that my dissemination plan includes presenting my research to Māori organisations in Christchurch, for example, to Te Putahitanga. Furthermore, both Phases of the research collected ethnicity data, and as a New Zealand citizen, and a member of the local iwi, Ngāi Tahu, I am aware of the Treaty of Waitangi and Māori models of well-being such as Te Whare Tapa Whā. I also welcomed any discussion of, or concern regarding, cultural considerations deemed important by participants.

Engagement with the disability community was conducted through two ways. First, the research proposal for my thesis was presented to the Burwood Academy Consultation Committee (BACC⁵), a national consultation service that enables researchers to present their research proposals in the field of disability and rehabilitation to individuals living with a variety of impairments, for consultation regarding the topic, methods, dissemination, and disability education. BACC requested that consideration be given to individual and social factors influencing participants' experiences (see Appendix B). Second, presentations were conducted to disability organisations, such as the Earthquake Disability Leadership Group (EDLG), as the research progressed.

3.7 Ethical considerations

Both Phases of my research received ethical approval from the University of Canterbury's Human Ethics Committee: Phase One reference: HEC2014/57, and Phase Two HEC2015/117 (Appendices C and L). Of note was that for both Phases of the research, it was acknowledged that the 2010/2011 Canterbury earthquake sequence and time since has been a significant experience for many people. It was possible that participants in both Phases could become upset thinking about certain aspects of their experience. In response to this, participants were provided with information sheets that included contact phone numbers of local counselling services. If any participants felt the need for further assistance, one of my supervisors (Dr Deborah Snell, a registered Clinical Psychologist) was available to discuss referral options.

3.8 Summary

To summarise, this chapter has outlined the main theoretical underpinnings that informed the research design and methods used to address the research question and aims of my thesis. The methodology used was founded in the pragmatism paradigm, which facilitated an abductive, intersubjective, and transferable framework, which

⁵ In the interests of transparency, I was the Chair of BACC when the research proposal for my thesis was presented. To avoid conflict, another committee member handled all aspects of the consultation process for my proposal.

applied to the context of my research. The values of social justice and equality were also implicit throughout the design and framing of the methodology and methods used in my thesis. The specific methods used in each phase of the research are described in detail in Chapters Four and Five respectively.

Chapter Four: Phase One – A Qualitative Study

4.1 Introduction

The first phase of my research employed an exploratory design. The unique intersection of participant group (wheelchair users), hazard type (an earthquake), and timeline (four years post-disaster), warranted an exploratory, qualitative study to provide a thick description of participant experiences in which a deeper understanding of the phenomena might be achieved (Braun & Clarke, 2013).

Phase One of my research proceeded via two steps. First, participants were invited to partake in an individual semi-structured interview. All interviewees were then invited to a single group interview where a summary of the interview data was presented for discussion and debate. The purpose of the group interview was to clarify and prioritise key components of importance for the survey. This combination of methods reflected a pragmatic approach to understanding the potentially diverse range of individual and social determinants of inclusion and participation experienced by wheelchair users during the longer-term recovery of the Canterbury community following the 2010/2011 earthquakes. Ethical approval for Phase One was received from the University of Canterbury's Human Ethics Committee (reference: HEC2014/57, see Appendix C). The findings of Phase One have also been published in *The International Journal of Disaster Risk Reduction* (Bourke, Hay-Smith, Snell, & Schluter, 2017; copy included, see Appendix T), and being the subject of oral presentations to The New Zealand Rehabilitation Conference, October 2015.

4.2 Aims

The aim of Phase One was to understand what people who use wheelchairs perceived to be the individual and social determinants of inclusion and participation in the Canterbury community in the four years post-earthquake.

4.3 Methods

The reporting of this qualitative component was conducted in line with the consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (Tong, Sainsbury, & Craig, 2007)

4.3.1 Theoretical assumptions

The theoretical framework informing the overall project was pragmatism, which is focused on answering research questions in practical, action-orientated ways, and acknowledges that researchers may have to use a mix of methods to best achieve this (Cornish & Gillespie, 2009; Johnson & Onwuegbuzie, 2004). The specific theoretical assumptions underpinning Phase One drew on critical realism. Critical realism acknowledges the subjective interpretation of an external reality, which is embodied within historical, social, political, and cultural influences (Fade, 2004; Guba & Lincon, 1994; Smith, Flowers, & Larkin, 2009).

Critical realism has been promoted as an ideal paradigm in which to examine disability (Bhaskar & Danermark, 2006; Shakespeare, 2014; Williams, 1999). One strength of critical realism is that it can avoid the pitfalls of reductionism, or essentialism, associated with the worldviews of certain disability models, such as the biological essentialism associated with the individual model, the structural essentialism associated with the social model, and the discursive essentialism associated with postmodern theories (Bhaskar & Danermark, 2006). For example, Williams (1999) contends that critical realism can encompass both the role of the body and society in creating disability, “without stripping agency of agency, or structure of structure” (p. 798). These advantages of critical realism reflect an ontological and epistemological pluralism, in that critical realism is maximally inclusive and able to accommodate a variety of mechanisms and contexts in which the reality of disability can manifest (Bhaskar & Danermark, 2006).

I felt that this position was the most appropriate for this phase of the research, as the exploratory nature of Phase One needed to be open to a wide variety of unanticipated determinants of community recovery following a disaster. For example, participants’ experience might be influenced by a number of personal factors such as (but not limited to) age, gender, personality, impairment, attitudes, wheelchair type, and other aspects of their worldviews created by past experience. Aspects of the wider context that might influence experience might include the type of political context in which one lives, socio-cultural reactions and assumptions towards people who use wheelchairs, and dynamic manifestation of social and family support.

4.3.2 Participants

To be eligible for Phase One, participants were required to use a wheelchair as their main form of mobility. To understand the wide range of experience, a diverse sample was desired. For example participants were sought who varied regarding their impairment, the type of wheelchair they used, the time spent using a wheelchair, living situation, age, gender, and ethnicity. To be included, participants were required to:

1. use a wheelchair as the main form of mobility (defined through participants self-reporting wheelchairs as the main form of mobility);
2. currently live in the greater Christchurch area (defined by district boundaries);
3. be 16 years of age or older; and
4. be able to engage in a method of understandable communication with the researcher.

4.3.3 Recruitment and participation

To recruit participants, organisations whose membership included people who use wheelchairs were asked to circulate an invitation to their members (Appendix D) to participate in the study. These organisations were CCS Disability Action, the Earthquake Disability Leadership Group, the Burwood Academy of Independent Living, the New Zealand Spinal Trust, and the Multiple Sclerosis Society. A recruitment poster (Appendix E) with contact details was also placed in public areas such as the University of Canterbury, Christchurch hospitals, and various supermarkets. The recruitment poster asked for interested individuals to contact me (JB) for an information pack that included a cover letter (Appendix F), an information sheet (Appendix G) explaining the background and purpose of the research project, and a consent form (Appendix H). Thirteen people contacted me expressing interest in participating and were sent an information pack. Those 13 people were then sent a follow up email one week later asking if they were still interested in participating, and if so, what date, time, and location would suit them for an interview. All 13 people agreed to participate in Phase One. No further people contacted me, and following Braun and Clarke's (2013) guidelines, a sample size of 13 participants was considered sufficient for Phase One. Braun and Clarke (2013) recommend 6-10 interviews for a

small qualitative study using thematic analysis; large enough for identifying patterns across cases, yet small enough to focus on individual experiences. Patton (2002) contends that sample size in qualitative research is guided by the purpose of the inquiry, and the purpose of Phase One was to gain insight into detailed, specific experiential knowledge of a small sample that shares a contextual experience (i.e. living in Christchurch following the 2010/2011 earthquakes) to help interpret themes that informed the survey used in Phase Two of the research.

4.3.4 Individual interviews

Interviews were conducted at a location of the participant's choice that was convenient and accessible. Participants were informed that they could have a support person present at the place of each interview, and that they could take a break or stop the interview at any time, and could choose not to continue without having to give a reason why. Prior to obtaining consent, participants were asked if they were satisfied with the information provided and whether they had any questions. Consent was obtained through participants signing a consent form prior to the interview commencing. Interviews were semi-structured and based on an interview guide (Appendix I) ensuring a certain set of topics were presented in each interview. Each interview was envisioned to be approximately one hour, so as to not be too exhausting for participants. However each interview was flexible and specific to each person. Questions were ordered from the broad (e.g. what does the word 'community' mean to you?) to the more specific (e.g. do you feel there are any environmental factors that can act as a barrier or support to being included in the community?). However, the questions were open-ended so that the interviews were ultimately guided by the needs and concerns of participants. Various prompts were also used to explore questions in more detail (e.g. why do you think that was? Can you think of an example?). In addition to the topics outlined in the interview guide, participants were also asked to discuss any aspects of their community inclusion experience that was not included in the questions asked but were important to them. All participants received a grocery voucher as *koha* (gift) for their time.

4.3.5 Group interview

The group interview was viewed as an intermediate step between the individual interviews and survey development. The aim of the group interview was to present a

summary of the interview data for discussion to help to clarify and prioritise key components of importance for the survey. All participants who were interviewed individually were invited to participate in the group interview. Participants were invited to ask any questions prior to signing a consent form. Participants were informed they could take a break from the group interview at any time and choose not to continue without having to give a reason why.

Group interviews differ from focus groups in that the facilitator can play a more prominent role in directing discussion. A group interview was considered appropriate so that I could direct the discussion by presenting a preliminary analysis of the interview data. Nevertheless, the group interview was exploratory; the interview guide was semi-structured with questions and prompts designed to allow for unanticipated ideas to emerge. It is common to use exercises or stimulus material to encourage conversation in group interviews (Kitzinger, 1995; Kroll, Barbour, & Harris, 2007). In this instance I presented the five candidate themes identified in the interview data, and prompted (Appendix J) participants to discuss and debate. Participants were encouraged to discuss things interactively between one another. To ensure all participants present contributed, I would ask the opinion of participants who less frequently made contributions. The group interview was intended to run for approximately one hour, in a location that was convenient and accessible.

4.3.6 Data analysis

Individual interview and group interview data were subject to thematic analysis, a flexible approach that can be used to identify, analyse, and report patterns within data (Braun & Clarke, 2006, 2013). The six stages of thematic analysis suggested by Braun and Clarke (2006) were used, and data were managed using the qualitative data analysis software NVivo (Version 10: QSR International Pty Ltd). An independent transcriber, who signed a confidentiality agreement (Appendix K), transcribed all of the digital recordings of individual interviews, and the digital recording of the group interview, verbatim.

First, individual interview transcripts were uploaded to NVivo. Interviews were read and re-read to familiarise myself with the data. Initial ideas and items of interest were recorded in a 'memo' document for each transcript. The second step advocated by Braun and Clarke (2006), was to generate codes that reflected single concepts in the

data. To achieve this, any ideas or concepts in the interview transcripts that I interpreted as relevant to the research question were highlighted and assigned a code that was saved on NVivo (examples of codes were: *independence is important*; *earthquake changes social dynamics*; *disability community needs to be vocal*; and, *consultation with people living with disability important*). As the analysis of transcripts continued, each idea was coded under a pre-existing code or a new code was created to capture a new concept.

Once all transcripts were coded the third stage was to organise these codes into broader patterns, which would form the basis of themes. This was achieved by listing all codes in one of two categories: individual-related codes, and social-related codes (these categories reflected the research aim of Phase One). This list was printed and patterns were identified through visually examining the codes, taking notes, and arranging similar and related codes into groups, which then became the candidate themes. A central organising concept, or definition, for each candidate theme was created. A folder for each candidate theme was then created in NVivo and the codes assigned to each candidate theme were moved to the appropriate folder. This created a document for each candidate theme that included all of the codes for that candidate theme, and every coded excerpt assigned to those codes from 13 transcripts. Each candidate theme document was then printed, read, annotated and a candidate theme definition of 100-200 words was developed.

The fourth stage advocated by Braun and Clarke (2006) involves reviewing and refining themes, specifically in relation to the whole data set. It was at this stage of the data analysis that the candidate themes were presented at the group interview for further discussion and debate. The transcript from the group interview was printed and read in conjunction with each candidate theme document and notes were taken regarding any ways in which the group interview transcript supported, challenged, and/or developed the original candidate themes. This enabled a robust review of the candidate themes to be conducted, and importantly, as Braun and Clarke recommend, enabled the themes to be interpreted and refined in relation to the whole dataset.

The fifth stage involved the final refinement and naming the themes. To achieve this, a summary of how the group interview data contributed to each candidate theme was written, and extracts that reflected these contributions were highlighted. This enabled

a more nuanced understanding of the themes derived from the individual interviews and at this point the candidate themes progressed to the final themes.

In the sixth stage, a final analysis and write up was conducted. An overall narrative was written that linked all five themes and specific extracts that illustrated the essence of each theme were selected from both the interview and group interview data. A key outcome of this stage was to ensure that all themes were integrated in a way that “goes beyond description of the data, and makes an argument in relation to the research question” (Braun & Clarke, 2006, p. 93). This integrated narrative was circulated to all supervisors for comment and a meeting was held to discuss and verify the coherence between the themes, the chosen extracts, the overall narrative and the relation to the research question. This integrated narrative formed the basis of what is the results section below.

With regard to ensuring data analysis was conducted in a rigorous manner, several quality control measures were used. First, all thesis supervisors read a sample of the transcripts and regular meetings were held with these supervisors throughout each step of the thematic analysis. This helped to ensure the interpretation of the data remained consistent with the research question and the theoretical underpinnings of the research, i.e. pragmatism and the focus on practical outcomes, and identifying the issues people face in the real world (Cornish & Gillespie, 2009). Second, the group interview served as a way to validate the five candidate themes. For example, for every candidate theme, all participants at the group interview were asked if they felt that theme reflected their experience. This enabled a robust review of the candidate themes to be conducted, and importantly, as Braun and Clarke recommend, enabled the themes to be interpreted and refined in relation to the whole dataset. Through using the above measures, I felt confident that data saturation with regard to the research question had been sufficiently reached. Third, a complete record of the data collection and data analysis process was kept so that an independent researcher could evaluate the process taken in establishing the results of Phase One. Fourth, explored below, I practiced reflexivity regarding my position and role in the research design and knowledge production.

4.4 Results

The study sample consisted of 13 participants, (7 women, 6 men). Table 4.1 outlines the demographic information (categories were pooled to reduce the possibility of identifying participants due to New Zealand's relatively small population). The mean age of participants was 49.3 years (range: 24 – 74 years), and the mean time of wheelchair use was 23.4 years (range: 3.5 – 47 years)

Table 4.1. Demographic information of participants in Phase One, at individual interviews (n=13) and for the group interview (n=5).

| Characteristic | Individual interviews | Group interview |
|--|-----------------------|-----------------|
| | n (%) | n (%) |
| <i>Age (years)</i> | | |
| 20–39 | 3 (23) | 1 (20) |
| 40–59 | 7 (54) | 2 (40) |
| 60+ | 3 (23) | 2 (40) |
| <i>Gender</i> | | |
| Male | 6 (46) | 2 (40) |
| Female | 7 (54) | 3 (60) |
| <i>Ethnicity^a</i> | | |
| New Zealand European | 11 (85) | 4 (80) |
| New Zealand Māori | 2 (15) | 1 (20) |
| Other | 1 (8) | 0 |
| <i>Impairment</i> | | |
| Cerebral Palsy | 3 (23) | 1 (20) |
| Spinal Cord Injury | 8 (62) | 4 (80) |
| Spina bifida | 1 (8) | 0 (0) |
| Other | 1 (8) | 0 (0) |
| <i>Time using a wheelchair (years)</i> | | |
| 0–19 | 4 (31) | 3 (60) |
| 20–39 | 7 (54) | 1 (20) |
| 40+ | 2 (15) | 1 (20) |

Note: ^a Ethnicity was through self-identification, and multiple responses possible.

For the individual interviews, six participants chose to be interviewed in their homes, three participants chose to be interviewed in a quiet public café, two participants chose to be interviewed at my university office, and two participants chose to be interviewed at their workplace. I conducted all interviews, which ranged between 35–60 minutes and were all digitally recorded and transcribed verbatim. One participant out of the 13 chose to have their assistant present primarily to help me understand the participant's pronunciation. The assistant's comments were included in the transcript

and were mainly clarifications of the participant's comments. To validate the assistant's comments I asked the participant to confirm whether they agreed with assistant's comments, either through a yes/no verbalisation or a nod/shake of their head. Furthermore, the participant made it clear before the interview that the assistant and the participant had a close relationship and the participant regularly used this approach to communicate with others.

All 13 participants were invited to participate in a group interview. While multiple dates and times were proposed, none suited all the participants due to other commitments. Nine was the greatest number of participants that could be accommodated, and five took part. Of that five, three were women and the mean age of participants at the group interview was 54.6 years (range: 29 – 74 years). Four participants identified as New Zealand European, and one as New Zealand Māori. The mean time of wheelchair use was 17.7 years (range: 3.5 – 47 years). Three participants used manual wheelchairs, and two used power wheelchairs as their main form of mobility. One participant brought their spouse as a support person. The spouse's comments were transcribed but not subject to analysis. The group interview was one hour long and took place in a room at a rehabilitation hospital with accessible toilets and car parks. The digitally recorded group interview was transcribed verbatim. All participants present at the group interview took part in the discussion.

Five themes captured my interpretation of participants' perceptions of their community inclusion experience post-earthquakes. The findings outline an integrated account of the data analysis: capturing the complexity within and between the five themes.

In the first theme, titled *earthquakes magnified barriers*, participants explained how they experienced numerous barriers to community inclusion, and that many pre-existing barriers were magnified by the earthquakes. Magnified barriers reduced participants' degree of community inclusion and participation and created feelings of difference and frustration. In the second theme, entitled *community inclusion requires energy*, participants articulated that at an individual level they were required to expend a great deal of energy to negotiate the barriers outlined in theme one. This energy was required prior to the earthquakes, and was increased by the consequences of the earthquake. The third theme, named *social connections are important*, captures

how participants' social connections were a defining feature of community connection, and provided a sense of belonging, support, contributed to participants' wellbeing, and encouraged greater community inclusion and participation. In the fourth theme, labelled *an opportunity found?* I describe how a unique opportunity exists to build an accessible city, and that the potential realisation of this opportunity will play a key role in determining whether people who use wheelchairs feel included in their community. In the fifth and final theme, *an opportunity lost?* I outline the concept that central and local government, alongside private industry could fail to influence accessibility in the Christchurch rebuild.

The five themes were established during the analysis of the individual interview data and refined during analysis of the group interview data. Analysis of the group interview data reinforced the notion that the magnified barriers, and the energy required to negotiate them, increased isolation, and decreased social interaction and feelings of community inclusion. All quotes used in the results section are derived from individual interviews, unless preceded by the letters 'GI' to denote that they are from the group interview. Before describing each theme in detail, the next section briefly explores what the concept of community meant to participants, thus defining community throughout the results of this analysis.

4.4.1 Participants' concept of community

The principal components of participants' concept of community were people, places, and the interaction between those people and places. First, in terms of people, participants described community as family, friends, neighbours, work colleagues, and members of the public: *"to be in a community is to be with people and not people you already know but to have actual interactions with people around you"* (Participant 3). Second, in terms of places, participants made many references to the physical environment: their house, their streets and local neighbourhoods, shops and businesses, their children's schools, and public spaces within the city.

The third important component of participants' concept of community was the interaction between people and places. This interaction was described by participants using verbs (such as supporting, interacting, helping, contributing, engaging, sharing, and including) that described how their 'community' behaved. The interactive nature of community was captured by one participant:

it's just basic stuff like people ringing to catch up, you know 'I want to come round and catch up' or people ringing to say 'Look, I'm going to this' or you know, 'Do you want to come with me?' or 'we're having a dinner party' or 'do you want to go to the movies?' or, or neighbours saying 'hi' on your way down the driveway (Participant 13).

Participants emphasised the reciprocal nature of the community interaction, describing instances where others were supportive and helped them, and conversely, when they helped and were supportive towards others: *"it really means a lot to me to be able to get out in the community and share with them and they share with me"* (Participant 1).

Having identified the key elements of the participants' concept of community, community inclusion is defined (in the context of my research study) as a product of how well participants could interact with the people and in the places that were important to them. For example, how easy is it for someone who uses a wheelchair to contribute, engage, and be in the place with the people that are important to them, being involved in shared, meaningful, activity? As one participant said:

it's good to get out because your friends they know where you're at and often they would come and help me get my chair down from the back of the car... they felt part of me and I was part of them, and if I didn't show up one day, they were kind of sad, you know, 'Where's P10?', 'Where's he gone?' you know, so they would give me a ring to make sure that I was able to go and if I wasn't able to go that particular day, they would change the day to suit me (Participant 10).

Participants said that they felt community inclusion following the earthquakes was more of a challenge for people who use a wheelchair. The themes described below explore the various sources of these challenges.

4.4.2 Theme One – Earthquake magnifies physical barriers

Participants explained how they experienced numerous barriers, and how the earthquakes magnified these barriers, reducing community inclusion and participation and creating feelings of difference, frustration, and isolation. Before the earthquakes

participants faced a number of physical barriers in the community. Examples of these barriers included inaccessible houses, a lack of accessible car parks, difficulties in accessing curbs, and inaccessible shops and businesses. Following the earthquake the most frequently mentioned barrier was the physical disruption to footpaths and roads. These barriers were not only stressful but actually deterred participants from wanting to go into their community:

I'll be stuck with not knowing where a footpath will be blocked off halfway and I have to go all the way back and cross the road to the other side of the footpath and you know it's really stressful, so I avoid going to town if I really don't have anything to do there (Participant 12).

Another participant described the physical disruption to the footpath outside their house and the impact it had on their ability to engage in meaningful activities in their local neighbourhood:

where I live, the footpaths are still totally inaccessible going left out of our gate... it actually made me feel quite isolated and you know, stuck in my house, because I was used to taking the dog for a big long walk right round the block, it was just impossible, and that footpath is still the same, four years later, hasn't been done, it's just broken (Participant 7, GI).

Negotiating these physical barriers was not only a deterrent to community inclusion, but also exposed participants to hazards such as having to go onto the road in order to find a way through. Participant 10 said: “*so many fences are up and that sort of thing and you've gotta sort of go out into the roadway which makes it, you know, hazardous*”. Participant 11 concurred “*often I have to um... put myself in danger on the roads because there's no other alternative*”. Participants described how the time-consuming and hazardous consequences of these barriers cumulated in feeling unable to “take part” in the community:

If we can't get in then how can we take part, if you know you can't get past the road cones or you can't get up the curb because there's no curb cut down because they've blocked it off and they haven't bothered to put a temporary one down or whatever but if they don't do that stuff then how can you take part because that's the real barrier (Participant 1).

In this extract the participant referred to ‘taking part’, which implies wanting to contribute to the community and have opportunities to be involved. This looks past the immediate consequence of the physical barrier, i.e. moving along a footpath, to the longer-term consequence – an inability to ‘take part’. This was the most important consequence of these barriers, as illustrated at the end of this extract: ‘that’s the real barrier’. Having adequate physical access is an absolute necessity for people who use wheelchairs to literally move from point A to point B, and consequently, take part in the community. As such, physical barriers can have a much larger impact on people who use wheelchairs compared to people who have greater mobility and may be able to negotiate those barriers more easily.

Another barrier magnified following the earthquakes was finding accessible housing. Before the earthquake participants described this as being a challenge. After the earthquake, with so many homes damaged and/or in need of repair, the demand for housing increased substantially. This made finding accessible homes for wheelchair users even more difficult. As Participant 13 remarked:

the earthquake’s had a big effect there because I had to move out of the house, I’ve had four shifts in the last four years so um, it’s more finding a rental that has the least alterations that you need to do to it... landlords are a little bit fussy so yeah... you’re competing with a much, a much larger pool of people looking for rentals.

This extract shows how participants faced two challenges in regard to finding accessible housing. The first was having to compete with the much larger pool of people looking for rentals, and second, the challenge of finding either an accessible house or a house where the landlord was open to having alterations. Demand for housing is still very high four years following the earthquakes (Canterbury Earthquake Recovery Authority, 2015a). Participants felt finding accessible housing was still a major issue. For example, at the time of her interview, Participant 8 still had not had repairs completed and they were quite aware of the difficulty they will face in finding temporary accessible accommodation: “*probably the thing I’m most concerned about is finding somewhere to live while it’s fixed cause it’s gonna be like about four months it’s going to take*”.

The importance of having an accessible house cannot be overstated for a person who uses a wheelchair. For example, one person considered leaving Christchurch due to the impact of the earthquake and her first thought was finding accessible accommodation: *“for a long time (post-earthquake) I wanted to leave, like really wanted to leave but the reality is I’ve got a house here – it’s accessible I’ve got a job and if I go anyplace else that doesn’t exist”* (Participant 1). For people who use a wheelchair as their main form of mobility, having an accessible house is a non-negotiable requirement. Due to their rarity, accessible houses are a highly valued resource for people who depend on their design and availability. As such, having an accessible house can play a significant role in determining the geographical place a person decides to live.

Participants described how they felt many barriers to community inclusion reflected a lack of understanding and appreciation of the needs for people who use a wheelchair by society as a whole. For example, one participant described how an accessible car park was compromised by being blocked: *“a car park yesterday at Tower Junction, they had lovely wheelchair car parks but the ramp up onto the footpath had an able-bodied car parked in front of it”* (Participant 6). As another example, a participant described footpaths that had been rebuilt on such an angle that pushing a wheelchair became a challenge:

they rebuilt it but the foot path is on a camber like that (uses their hand to demonstrate level of camber) and there’s one which isn’t probably quite as bad but still quite steep in my view on the corner of (road name) and (road name) right in the middle of (suburb) there so you know there’s that kind of thing happening which makes me quite uneasy (Participant 1).

Having to repeatedly face barriers was frustrating and reduced independence. Participants felt that this actively deterred community inclusion, and also created feelings of difference and discrimination:

I want to be fully able to do things myself and I’m starting to think, “Oh, I won’t go there because I can’t get in” but how annoying that is, how discriminating that is (Participant 9, GI).

Barriers also contributed to participants feeling isolated. For example, one participant explained how the cumulative pressure that resulted from repeatedly encountering inaccessible places made it easier to just stay at home:

And it does build on itself... if you go out three times that week and you get three times you can't get in, you might only go twice next week because you can't be bothered, it's easier to stay home, and you know, read the paper or jump on the computer (Participant 13, GI).

As the two above extracts demonstrate, barriers could reduce the experience of, and opportunity for, community inclusion and contribute to feelings of frustration, difference, and isolation. This combined to create a considerable drain on participants' energy resources, which is specifically explored in the next theme.

In summary, the earthquakes magnified pre-existing barriers which made getting about in the community using a wheelchair a challenge. Many of the barriers described by participants were physical barriers such as inaccessible footpaths and houses; however, the physical environment does not occur in a vacuum: it is inevitably connected with political decisions and cultural norms. In theme two I explore how negotiating the magnified barriers described in theme one also magnified the energy required of participants at an individual level.

4.4.3 Theme Two – Inclusion takes energy

In theme two I contend that a major consequence of negotiating the magnified barriers outlined in theme one is an increased demand on participants' energy levels. People who use wheelchairs are often already experiencing more fatigue compared to people who do not use wheelchairs. This fatigue is due in part to their physical impairments and having to push a wheelchair (Nooijen, Vogels, Bongers-Janssen, Starm, & van den Berg-Emons, 2015; Rice, Rice, & Mofi, 2015). Participants articulated that at an individual level they were required to expend a great deal of physical, psychological, and emotional energy to negotiate the barriers outlined in theme one. This energy was required prior to the earthquakes, and was increased by the consequences of the earthquakes. The more energy participants had to expend facing barriers, the less likely they were to experience community inclusion.

Energy was needed to participate in the community prior to the earthquakes and was required to face challenges such as inaccessible environments or social interactions whereby people had little understanding or regard for disability or accessibility issues. Participants explained how the pre-earthquake baseline energy demand required to engage with the community was significant, and felt like a constant fight, or a constant level of awareness or vigilance that participants found exhausting when added to the general day-to-day pressures of life. For example, one participant found dealing with a well-intentioned public was helpful, and also tiring. People would often want to help them get the hoist down from the roof of their car, and while they appreciated the offer, operating the equipment required specialised knowledge and people who were not familiar with the equipment could easily break it. Having to explain this on a regular basis was tiring.

Participants often had to assess whether the benefits of community engagement would outweigh the energy that it would require:

I think the first thing when someone invites you somewhere or you want to do something, you're not thinking, "Do I want to do it?" you're thinking, "Can I do it?" That sometimes is when you go "It's just not worth the effort because of where you're going to meet, I can't get there or it's no parking"
(Participant 9, GI).

Another participant described having to have a constant awareness of accessibility issues when in the community, such as looking for wheelchair parking and deciding whether to interact with people who may be using the parks illegally:

I feel that ten percent of me's got to fight all the time, fight for my rights, and even just things like wheelchair car parking in the community, I'm very, very strong at not sitting back waiting if I see people in a car park that shouldn't be
(Participant 6).

This baseline pre-earthquake energy demand was considerable, and became magnified following the earthquakes. Post-earthquakes, extra energy was needed to face magnified challenges such as trying to find accessible rental accommodation, negotiating construction on footpaths and roads and having to drive new routes in their wheelchairs, and having friends or carers move away. Participant 13 remarked:

I think it's exacerbated it really, it just, life's hard enough in a wheelchair, life should be easy when you walk out the door, if it's harder when you walk out the door because you know, there's no transport or the roads are rough, or the buildings aren't there and the facilities aren't there, it just adds another difficulty or stress to the whole thing, so I think it's, it does magnify the whole issue.

A specifically exhausting challenge was trying to find accessible accommodation following the earthquake due to a much greater demand for accommodation in general. The energy required searching for accessible accommodation on the Internet, in newspapers, through social networks, and attending open homes was draining. With a lack of accessible houses available, participants would be in a position of having to ask landlords to alter a house to make it accessible. This put people who use wheelchairs at a disadvantage, when other potential renters were not asking for any financial outlay from the landlord, and added an extra psychological demand to a growing list of earthquake related concerns (such as dealing with insurance claims):

you've got twenty other couples or people looking at a flat, and you say 'yeah, I'd love to take it but can I just, give me two months until I alter the bathroom,' and they've got twenty other people that'll move in tomorrow... so that's just an added stress and, you know, the stress of dealing with insurance and earthquake damage to home and trying to get repairs going and all that sort of thing, so yeah, it was another stress I could have done without really (Participant 13).

Finding accessible accommodation was difficult, and the anticipation of having to potentially oversee the process of alterations added an extra layer of stress. A further energy-intensive challenge was negotiating a physical environment that the earthquakes had made even more inaccessible and testing. Four years post-earthquakes participants found that footpaths were often still cracked or uneven, and there were often obstacles or detours that were difficult to negotiate. Having to push and negotiate a wheelchair through this environment was physically and mentally exhausting:

I find there's a lot of problems when you're going down streets, it's an up and down ride, it's bumpy, they're not thinking of people in wheelchairs or, or whatever, because the roads or the footpaths, in particular, are at such an angle, by the time you get to the end, if you're pushing your chair, you know, it's hard going (Participant 10).

Participants also reported that energy was required to address the consequences of the post-earthquake environment, such as repairing footpaths. Participants described that they often had to make repeated efforts to contact relevant authorities (e.g. local council) and found progress to be slow. Other participants wanted to advocate for increased accessibility regarding post-earthquake barriers but said they did not know where to start, or did not have the energy to focus on what was yet another challenge:

I don't know how to interact with the authorities to try and make things more possible, every now and again I think maybe I should start trying to bang on someone's door and say 'You're not doing this the right way', but that requires energy, ... (and I have) a very finite amount of energy (Participant 9).

Exerting this energy on a constant basis was exhausting and became a barrier in its own right. The extra energy needed to face the post-earthquake environment was stressful and participants frequently described that it was easy to become isolated. If barriers were sufficient to overwhelm a participant's energy levels, the prospect of 'taking part' in the community became less likely:

I mean that's the bottom line, really, if it's harder when you walk out the door, you're less likely to go out the door and so, you know, you can become isolated (Participant 13, GI).

In a similar vein, another participant pointed out how they now have more hobbies at home, because the energy required to overcome barriers has deterred them from going out:

I find myself locked at home, it's created me to have more hobbies at home like my stamps and my coins and writing and books and things like that, and I just can't be bothered going out because I know those things are there so it's too much of a problem so I'd rather just skip it (Participant 10, GI).

As the two extracts above demonstrate, barriers and the energy required to face them, reduced participants' social interactions and community inclusion. Expending this extra energy was also a tax on participants' sense of identity. One participant described how the extra energy needed to negotiate the community environment put undue focus on her wheelchair, which was frustrating because she did not want the wheelchair to be such a big part of her identity: *"it can be so frustrating yeah just focusing on my wheelchair, it's only an object, it's not who I am"* (Participant 9).

In summary, a considerable pre-earthquake baseline energy demand was magnified by the consequences of the earthquakes, placing extra pressure on a finite energy store. The extra energy needed to procure accessible accommodation, negotiate physically challenging environments, and interact with the authorities that were tasked with improving the accessibility of the community, contributed to participants experiencing less community inclusion. In the next theme I explore the importance of social connections, and how they were a positive facilitator of community inclusion.

4.4.4 Theme Three – Social connections important

In this theme I focus on the idea of people and places outlined in the definition of community in section 4.4.1. Specifically, In this theme I explain how 'people' provided a strong sense of community for participants, and that the support received from social connections facilitated strong feelings of community inclusion.

For many participants, interaction in social situations was a *"must"* (Participant 10) and was a key feature in their definition of community. Participants frequently mentioned family, friends, neighbours, and work colleagues as their most important social connections. One participant also said it was important to have disabled friends as well as nondisabled friends, as many people living with disability can draw on a lived experience of facing common barriers, and only other 'insiders' can truly understand this:

even (my assistant) wouldn't even know... what it's like to, to have a disability or an impairment, like even though we might have a different impairment we have some things in common... (Participant 11).

Participants interacted with their social networks in a variety of ways. First, interaction within neighbourhoods increased a great deal following the earthquakes. This occurred through neighbours visiting one another and also through having communal street events such as barbecues. For many participants these connections remained strong even after four years. Strengthened neighbourhood networks encouraged feelings of community inclusion:

It makes you feel really good, it makes you feel just part of the community and yeah, that, to me has been the big bonus from the earthquakes, I would say, not many, but that would be the one (Participant 7, GI).

Second, participants also found their work environment was a valued source of social interaction, and that the social aspect of work provided a sense of support and reassurance:

I think I was home for two weeks and I said to my boss just let me come back to work this is just insane, I need to be round people... I have some kind of deep seeded feeling, if I'm around other people nothing bad can happen (laughs) (Participant 1).

Third, places such as cafes, parks, or events were an important factor within social interactions. Gathering and interacting with other people was made a great deal easier through having a physically accessible environment. As one participant said:

it's social but it also involves going different places to be with that community, I think of them as people so where would I meet with them? (Participant 9).

Inaccessible places impeded participants' ability to mix with their social networks, and enjoy the benefits that their social relationships afforded:

some places where I go, I can't get up, I can't go in because they don't provide ramps and you know, it's pretty hard and so I feel like, you know, I'm excluded from mixing with people I want to mix with (Participant 10).

The two extracts above relate to theme one and how physical barriers not only prevented mobility, but actually impeded a person's ability to take part in their social networks and relationships. Because people are an important part of community,

physical barriers to meeting with that community can indeed compromise community inclusion.

Lastly, social media also played a role in how participants experienced social relationships. Participants used social media to keep in touch with members of their social networks who were displaced following the earthquakes: *“I just find it’s really good, especially that I can keep in contact with my friends who have left Christchurch... it’s an important tool for me”* (Participant 2). However, participants also stressed that social media was not a substitute for face-to-face interaction.

The benefits of social relationships were numerous and diverse. Social connections provided support, reassurance, comfort, and a sense of belonging. The fundamental outcome of that support was that participants felt included in their communities. For example, one participant received a power chair from a member of their church community that enabled them to physically access many more places than they had previously known. Another example was family and friends who provided accessible accommodation to participants, which allowed them to stay in Christchurch. Furthermore, familiar social connections helped transition from pre-earthquake to post earthquake life, by acting as a constant value in an often changing and unpredictable environment. This helped to ensure that community inclusion was maintained:

my friends I’ve still got pre-earthquake but have helped me through the post-earthquake, like my sport, going to sports something I did before the earthquake, but I’ve kind of got that stronger connection because we’ve like all survived it (Participant 2).

Being included in the events of family and friends could also minimise the connotations of difference that often accompanies the use of a wheelchair. As one participant said:

I’m able to go to these groups and interact with them, and I’m able to share my story with them, sit with them and make it like I’m a normal person, you know, and that’s a ‘must’ I think, to be able to do things and make it look ‘Hello, I’m a normal person like anybody else’, you know (Participant 10).

As this extract describes, being part of social groups enabled participants to feel as though they were included, as opposed to becoming excluded and isolated. As a result, social interaction was very valuable to participants' sense of well-being. Many participants referred to this, making comments such as: *"the whole feel-good factor from socialising and communicating is very important"* (Participant 4). This benefit to participants' well-being was qualified by participants explaining that it was worth investing energy and motivation into initiating and maintaining social networks:

I think that social connections are absolutely vital but, you can't rely on other people to invite you all the time, so there's got to be some self-motivation there (Participant 13).

The important role that social connections played in facilitating community inclusion was also illustrated through participants' experiences of weakened networks and how these could contribute to less community inclusion. For example one participant had a close circle of friends move away from the area following the earthquakes. Another participant took retirement from their employment that was adversely affected by the earthquake. In another instance a participant had one or two carers move away following the earthquake and for a short period had to rely on their family more than usual. These examples showed how as a consequence of the earthquakes, social networks could be weakened and reduced participants' opportunities to stay connected to their community.

In summary, this theme is relevant to my research question in the sense that participants' opportunities to engage with their social networks provided a positive experience of community inclusion. Participants valued social interaction which occurred in a variety of ways, including neighbourhood get-togethers, the workplace, and meeting in places throughout the community. These experiences facilitated community inclusion through enabling participants to feel as though they were an integral and valued part of the social community, and thus increasing feelings of well-being. In the next theme I explore how an opportunity now exists to enable more social interaction and well-being through reducing the barriers discussed in theme one.

4.4.5 Theme Four – An opportunity found?

In the theme four I summarise participants' views that the post-earthquake context provides a unique opportunity to rebuild an accessible environment which could increase their experience of community inclusion. Participants were adamant that this could enable greater access to more public spaces, reduce their energy demands, enable them to engage in more social interaction and contribute to the community as a consumer, as well as enjoying the well-being that is associated with this community inclusion. As one participant said:

We all like variety, we don't want to be going out to the same place all the time, so if there's less barriers then you're more likely to go out and experience something different (Participant 13, GI).

The scale of rebuild is such that a significant change in the overall accessibility of Christchurch could be realised. Many participants described the need for an accessible city as absolutely vital: *"as a wheelchair user, access is always a fundamental thing that I've got to constantly look at"* (Participant 10). This opportunity exists primarily for public buildings and spaces, and private buildings used for commercial purposes. Specifically, this could include access into and around buildings, public car parks and toilets, and more accessible public spaces:

being able to park somewhere to get somewhere easily from the car to the place and then, to actually be able to get in and move around in that environment, and have things like access to disabled toilets without major hassle (Participant 9).

This extract demonstrated how access is more than just getting through a door or being able to park one's car; many participants described their desire to be able to access all parts of the community environment, and that there needs to be:

access into places without having to think about it, so that whole journey from home to transport to your destination and then into your buildings and between buildings and between venues in the city, it's really really important... so there's some good opportunities (Participant 5).

Experience of accessible cities overseas imbued some participants with the knowledge that rebuilding an accessible city here in New Zealand was a realistic expectation: *“I’ve travelled overseas and I know what’s possible”* (Participant 11). International experience of accessible environments had shown participants the feelings of independence and well-being that can result from using an accessible environment:

it’s fantastic and then when you decide that you’ve finished that and you want to go back to the motel over the road, you can just go over the path and you don’t have to wait for someone to come and help you across (Participant 9).

A number of participants highlighted the international attraction an accessible city could afford, such as the appeal an accessible city might have for tourism. One participant suggested that: *“we’ve got a blank slate, a blank canvas and so... let’s make it a city that the rest of the world looks at and goes, wow!”* (Participant 5).

An initial benefit of a more accessible community is improved access not just for people who use wheelchairs, but a vast portion of the community, for example people with impairments who do not use a wheelchair, the ageing population, people with prams, and people with bicycles. As one participant said: *“if you get it right for people with disabilities you’re actually going to get it right for everybody”* (Participant 11). Participants suggested there was no reason not to create an accessible and inclusive community for a large portion of the population:

obviously any renovations or, particularly new builds, should be all wheelchair accessible and easy, you know not just for wheelchairs but people with walkers, ladies with prams, people with you know, one leg or you know, limping because they’ve had a rugby injury or that sort of thing so there’s no excuse really not to do that, I don’t think (Participant 13).

A second benefit of a more accessible community is increased potential for more social interactions. Participants referred to ‘the feel good factor’ that comes from socialising and communicating and being involved in group activities without having to worry about accessibility. For one participant who had more than one member of her family who used a wheelchair, a more accessible community would make family interactions much easier: *“cos in my family, there’s me and my sister in a chair, so my*

family are not only thinking about me, but they also have to think about my sister” (Participant 2, G1). With regard to one’s well-being, another participant reported how the accessibility of a community affected their sense of citizenship and identity, remarking that an inaccessible community made them feel like a: “*second class citizen*”, whereas an accessible community makes them feel “*like a full citizen*” (Participant 11).

A third benefit of a more accessible community would be the opportunity to create a more inclusive community where the difference and discrimination that result from inaccessible environments reduced or even became a nonissue. For example, one participant remarked how they hoped in the future, people who use a wheelchair: “*can go where they want and just be a part of the community and not think about the wheelchair*” (Participant 8). Another participant reported similar thoughts, highlighting that an inclusive society would indeed reduce the barriers commonly encountered when using a wheelchair:

I just hope that it eventually leads to an inclusive society where you and I can decide to go out to any event and just get into a building and it not be a big drama we don’t have to go down the, the back alley way or through the back door or, that it just becomes a real normal part of how we do things (Participant 1).

As this extract suggested the opportunity exists for people who use wheelchairs to go to any place or event without it being a ‘drama’, and having to negotiate comprised accessibility, often developed in an ad hoc manner for example, through back doors. Suggesting that an inclusive society with greater access would enable people who use wheelchairs to feel ‘normal’ implies that this is currently not the case and that the barriers outlined in theme one, and energy expenditure described in theme two, can create feelings of difference and frustration. Indeed, one participant described how given the choice, they would use the energy they currently spent on barriers, on more productive endeavours:

Go to the movies, go to the gym, exercise more, just doing normal things that your friends would do, that you don’t, you wouldn’t normally have the energy (Participant 2, G1).

In summary, in theme four I described that the Canterbury rebuild provides a unique opportunity to create a much more accessible community. Four potential benefits of a more accessible city have been highlighted in this theme, including a more universally accessible city, increased opportunities for social interactions, increased feelings of well-being, and reduced feelings of difference and discrimination. A more accessible city could reduce the barriers and energy needs outlined in themes one and two, increasing participants' experience of community inclusion and the positive benefits associated with it. Despite these benefits, participants were concerned that this opportunity might not be utilised. This concern is linked to theme five, in which I consider the tension between accessibility as a universal public right and the regulations in which private developers operate.

4.4.6 Theme Five – An opportunity lost?

In theme five I draw on participants' concerns that this opportunity might not be utilised to its full potential. That is, the power that resides with decision makers by virtue of central and local government regulations, and the culture and demands of private industry could influence whether the opportunity outlined in theme four will be realised. This could also play a key role in determining participants' level of community inclusion.

First, participants highlighted the rarity of this opportunity. Participants were quite aware that the possibility of another opportunity such as this presenting itself was not likely. As Participant 5 mentioned: *"it's not once in a lifetime opportunity... the [effects of the] rebuild are going to span generations so it's just a once opportunity"*. There was concern that there is a small window of time to act and that the opportunity to rebuild an accessible community might be lost, alongside any hope of improving accessibility: *"absolutely this is the opportunity and if we don't do it I give up cause if we can't get it right now there's no hope"* (Participant 3).

To avoid losing the opportunity to rebuild an accessible city following the earthquakes, participants emphasised that consultation is vital to truly understand the lived experience of using a wheelchair. Participants acknowledged that while designers can be well meaning, disability communities needed to ensure that they were involved in the public debate. It was important for disabled communities to

speak up and be noticed, as there was a feeling that the rebuild would go ahead and that disability issues would not be considered. As one participant suggested:

I guess what I'm wondering is, if enough is being done, if we sit back and rest on our laurels now everything's happening so quickly... we need, if we are not at the forefront all the time... to me it's as clear as the light of day that you know if, there's a visible demand then... people will react (Participant 4).

Without this concerted effort from the disability community to be vocal regarding the needs to improve accessibility, participants were concerned that there would be very little political push and minimal drive from within the building industry to rebuild an accessible city. For example, participants believed developers would want to get their buildings up as quickly and as cheaply as possible, and only incorporate accessible features into their developments if law requires it, or if they can see the economic benefit of an accessible building. Participant 5 recalls being told by a developer that:

you're joking if you're thinking that a private developer is going to build a place accessible because it's going to cost them more... the only way they're going to do it is by law change.

This extract highlights the tension that can exist between the view that accessibility is an ethical requirement, and the right for developers to work within the means of the existing legislation. As one participant remarked:

what is the value behind people's understanding of accessibility, is it a pain to do... or do they think it's a moral necessity that everybody should be included (Participant 3).

Participants explained a number of situations in which developers could have more appreciation for investing in accessible projects. First, participants explained that having personal family experience of a person who uses a wheelchair could challenge the concept that accessibility is just an abstract idea, or something that costs money. Participant 5 described knowing a developer who “has a granny in a wheelchair”, and because of this intended to make his development accessible for wheelchair users, through making walkways wider than necessary and making sure there are many elevators. Another participant described having a son-in-law who was a project

manager, and that after the personal experience of meeting the participant; the son-in-law then understood the importance of accessibility:

he could never see the point of having to put accessible toilets into all these jolly places and then he met me and knew me and he realised that it actually was necessary but you know without any experience of anybody in a wheelchair it's only a theory to all those people isn't it (Participant 8).

Second, participants highlighted the longer-term economic benefits for developers of investing in accessible environments. For example one participant suggested how a more accessible building would attract more customers:

if they (developers) did build it accessible to universal design, they're gonna get more people through the doors and people are money, just because you've got a disability, doesn't mean you haven't got money (Participant 5).

This extract highlights that just because you experience disability or use a wheelchair, doesn't mean you do not have money to spend. Indeed, participants described how access often determined which businesses they chose to support:

I would avoid going to a lawyer there, if my lawyer was in that building, I wouldn't want to go there, if I had a dentist there, I wouldn't go, so you start choosing those people for how easy it is to get to their places (Participant 9).

This extract also highlighted the irony that when people who use wheelchairs cannot access an environment, others have little chance of interacting, understanding their needs, or considering them as potential customers. One participant called this the chicken and the egg:

they say that there's nobody in a wheelchair comes into this building, well there's nobody in a wheelchair that comes into the building because they can't get into the building you know it's that chicken and egg kind of thing (Participant 8).

In summary, participants felt that a potential lack of commitment from those making decisions regarding accessibility could risk the opportunity presented by the post-earthquake environment being squandered. Participants were concerned that

developers would not prioritise accessibility, and that getting most developers on board would require legislation that advocated for accessibility. Whatever the approach taken from private industry, participants reiterated that adequate consultation from local authorities and developers regarding the needs of people who use wheelchairs could greatly enhance opportunities for community inclusion.

4.4.7 Summary

Five key themes were identified that reflected how participants felt the 2010/2011 earthquakes influenced their experience of community inclusion over the last four years. The five themes stand alone and are also interlinked and combine to determine participants' level of community inclusion and participation.

Perhaps the most direct impact of the earthquakes on community inclusion for participants over the last four years was that pre-existing barriers were magnified (theme one). This not only made getting about in the community more challenging, but also increased the energy expenditure required by participants to get about in the community (theme two). These barriers, and the energy it took to face those barriers, reduced the ability of participants to be included in the community and were detrimental to participants' well-being. However the support provided by participants' social connections (theme three) was a valued resource and acted as a positive determinant of community inclusion. Social connections contributed to increased feelings of community inclusion by helping participants to negotiate the barriers and increased energy needs following the earthquakes. However, the barriers and energy requirements outlined in themes one and two impeded participants' ability to engage with their social networks, creating feelings of isolation and a reduction in the benefits of social engagement and community inclusion.

In themes four and five the analysis was more focused on the possibilities participants felt were inherent in the post-earthquake rebuild. The opportunity for change described in theme four raised the prospect that many of the barriers identified in theme one could be removed, which in turn would also reduce the energy expenditure required of participants outlined in theme two, and encourage the benefits of having more social interaction outlined in theme three. Participants felt the stakeholders referred to in theme five (central and local government, and the private building

industry) will play a role in whether or not the opportunity for change is realised, and as such theme five is implicitly connected to the first four themes.

4.5 Discussion

While a full interpretation and discussion of findings will be conducted following the completion of Phase Two, tentative implications of Phase One findings can be drawn at this stage. First, this discussion examines how these findings of Phase One align with the argument that a greater emphasis is needed on the social context in which disaster recovery occurs as opposed to framing people living with disability in terms of individual vulnerability. Second, this discussion examines how the findings of Phase One align with the argument that disability organisations should be leading partners in the recovery process. This discussion concludes by reaffirming the role of the Phase One findings in forming a foundation for Phase Two.

4.5.1 Expanding beyond ideas of individual vulnerability

As highlighted in theme one, pre-existing barriers to community inclusion can be magnified following a disaster. This concept was discussed by Peek and Stough (2010), who claimed that due to social, economic and political factors, existing inequalities experienced by people living with disability can be magnified during a society's response to a natural disaster. As a result, certain populations that might have had minimal resources prior to disaster, can have even less access to resources after a disaster, making recovery even more challenging.

Many of the magnified barriers identified by participants in Phase One were related to environmental factors more so than the participants' impairments, challenging the viewpoint that vulnerability experienced by people living with disability in disaster contexts is a 'natural' outcome of their impairments. This viewpoint stems from traditional disaster planning and response culture that has largely framed disability as an individual 'condition', not a social situation (Winser, 2002). This stance is based on the individual 'medical' model of disability that assumes disablement is a direct consequence of a person's physical or cognitive impairments (Barnes & Mercer, 2003). The findings of Phase One support the argument posited by Priestley and Hemingway (2007), who argued that there is a great benefit to applying the social model of disability perspective when examining the vulnerability of people living

with disability in disaster contexts, contending that “just as disability is not the inevitable consequence of physical or cognitive impairment, disaster is not the inevitable consequence of natural hazard” (p. 25).

A social analysis of disability and disaster recovery can also be applied to the opportunity highlighted in theme four. Many authors have highlighted how the recovery period following a natural disaster offers a clear opportunity to rebuild an accessible, inclusive infrastructure for people living with disability (Phillips, 2015; Priestley & Hemingway, 2007). A key reason as to why this opportunity becomes so salient in the post-disaster context is that urban environments are very rarely presented with opportunities for such an extensive reconstruction. The scale of reconstruction following a disaster, like the Canterbury earthquakes, is of such a magnitude that the accessibility of public spaces and buildings can be dramatically improved compared to the infrastructure that existed pre-earthquake. The next section examines how this opportunity might be best realised, and the argument is made that it will be through partnership with local disability organisations.

4.5.2 Disability organisations as agents of recovery

Phillips (2015) contends that the recovery period represents an opportunity to rebuild not just *for* people living with disability, but also of crucial importance, *with* people living with disability. The findings of Phase One suggest that it is crucial for central and local government, and the private building industry, to engage in genuine partnership with local disabled communities to realise the opportunity for an inclusive recovery. Fjord and Manderson (2009) argued that placing the needs and expertise of disabled communities at the forefront of disaster recovery can have multiple benefits, for example tailoring recovery plans to the local context, promoting local expertise, and empowering local disability services.

An example of a disability organisation being involved in the Christchurch recovery process was the establishment of the EDLG in December 2011. Led by people living with disability, the EDLG was established to advocate for the rights of people living with disability during the recovery following the Christchurch earthquakes. The EDLG has achieved significant progress so far, ensuring access audits are being carried out on all major anchor projects at the tender, design, and construction phases, and considering ways to make public submissions on emerging policy initiatives

concerning the rebuild easier for people living with disability. The EDLG is also working to assemble information about accessibility in one place, ranging from information about submissions, to requirements of the building code, and links to relevant organizations (Earthquake Disability Leadership Group, 2014). The EDLG is a pragmatic example of how a disability organisation led by people living with disability can become involved in a disaster recovery process.

4.5.3 Towards a greater understanding

The final consideration of this discussion is to locate the results of Phase One within the overall research design of this study. My research used a mixed methods exploratory design, in which an initial qualitative phase aimed to explore phenomena where the variables or constructs are unknown, which then informed the development of a quantitative instrument designed to measure the prevalence of those constructs in a larger sample (Creswell & Plano Clark, 2011), (see section 3.5 for detailed description).

My research design is suited to the Canterbury context for a number of reasons: there are no instruments available to quantify wheelchair users experience of community inclusion following a natural disaster; there is little research exploring the longer-term impact of natural disasters on people living with disability; and understanding wheelchair users' experience of community inclusion in the first instance was best explored using a qualitative approach because detailed, rich information was needed due to the scant experiential knowledge on the topic and local context (Creswell & Plano Clark, 2011). Indeed, the small amount of research that has explored the experience of people living with disability in the initial period following the September 2010 earthquake recommended the need for more research as recovery-related initiatives developed (Phibbs, Good, Severinson, Woodbury, & Williamson, 2015).

The findings of Phase One fulfilled the role required of the initial phase in an exploratory mixed methods design, that is, to identify themes and patterns that can inform the development of an instrument to be used in Phase Two. Five themes cumulated to provide a twofold interpretation: the Canterbury earthquakes magnified pre-existing barriers to community inclusion, such as inaccessible footpaths and roads and a lack of accessible housing, *and* created an unprecedented opportunity to reduce

many pre- and post-earthquake barriers to community inclusion through reconstructing a more inclusive community. These findings provided an insight into a hitherto unexplored area, and established the foundation for the development of a survey that is the focus of Phase Two. The details surrounding the development of this survey are described in Chapter Five.

4.5.4 Strengths and limitations

In this section I outline a number of limitations and strengths specific to Phase One. The overall strengths and limitations of the entire thesis can be found in Chapter Six (see section 6.5).

Because Phase One explored first-hand accounts of people with particular functional needs, wheelchair users, the findings may not reflect the perspectives of people with other impairments, for example those with hearing, visual or cognitive impairments. In addition, with no sampling frame to indicate the population parameters of wheelchair users in Christchurch, the sample may not reflect the diversity within the wheelchair user population in Christchurch. For example, the sample in this study did not highlight any needs and issues pertinent to Māori (New Zealand's indigenous people). Future research should consider purposely sampling more wheelchair users who identify as Māori in order to illicit a more detailed and nuanced interpretation of Māori perspectives.

A potential limitation was that only five out of the original 13 participants participated in the group interview, and it is possible that the eight participants who did not attend the group interview may have shared different perspectives to those who did attend. Great effort was spent trying to organise a time to accommodate all participants, and unfortunately establishing a time which suited all participants was unsuccessful. Further, nine participants agreed to join the group interview, and only five attended. Despite this, data from the group interview served to clarify and provide examples of the original five themes (interpreted from the 13 individual interviews), rather than significantly altering them. As such, it is reasonable to assume that the final data analysis is reflective of all 13 participants.

Finally, the findings reflect a specific contextual experience of thirteen participants, a number considered sufficient for inductive thematic analysis; large enough for

identifying patterns across cases, yet small enough to focus on individual experiences (Braun & Clarke, 2013). To ensure rigour, every effort was made to provide sufficient detail (regarding the participant group, the context in which the research occurred, and the processes involved in the data analysis) so the reader may decide whether the results might warrant being transferred to other settings (Polit & Beck, 2010; Shenton, 2004).

4.5.5 Summary

This discussion explored how the Phase One findings reflected two arguments present in the disability and disaster literature. First, that a disabled person's exposure to risk and their ability to respond and recover following a natural disaster needs to expand beyond ideas of individual vulnerability and be considered within the context of social, cultural, economic and political factors. Second, that the findings of Phase One reflected the concept that utilising the expertise of local people living with disability is a positive step towards realising an inclusive recovery. In relation to the overall design of this study, the findings of Phase One have provided a detailed and nuanced interpretation of how a small sample of people who use wheelchairs have experienced community inclusion in the four years since the Canterbury earthquakes. How these results of Phase One informed the development of the survey in Phase Two is described in the next chapter.

Chapter Five: Phase Two – A Quantitative Study

5.1 Introduction

In Phase Two an electronic, national, cross-sectional survey was administered that was developed using the findings of the thematic analysis of Phase One. This combination of methods reflects the exploratory mixed methods design used in my research; the initial qualitative phase provides an understanding of potential constructs, which then informs a quantitative instrument designed to measure the prevalence and relationships of those constructs in a larger sample. Ethical approval for Phase Two was received from the University of Canterbury's Human Ethics Committee (reference: HEC2015/117, see Appendix L)

The aim of this survey was to gather current and retrospective data regarding community inclusion at three different time points, to quantify the themes identified in Phase One, and to explore patterns within and between sub-groups. Furthermore, Phase Two intended to compare and contrast what 'community inclusion' means for wheelchair users within a geographical region experiencing earthquake-recovery and wheelchair users residing in a geographical region not experiencing earthquake-recovery.

Phase Two also had a methodological aim with regard to sampling. As mentioned previously (see section 2.4), in the absence of a sampling frame for wheelchair users, an approach known as RDS was ideally positioned to provide a potentially representative sample. It is prudent to emphasise that this approach was novel, and had not been used before to sample people who use wheelchairs. However, RDS appeals as a sampling method in the digital age, and holds potential as a new survey technique in the field of epidemiology and disability. The experience of using the RDS approach has been published in a peer-reviewed journal (Bourke, Schluter, Hay-Smith, & Snell, 2016, copy included, see Appendix U). The publication contains an abbreviated version of aspects of this chapter.

5.2 Aims

The question explored in Phase Two was:

What do people who use wheelchairs perceive to be the individual and social determinants of inclusion and participation in their community, and is this different between those who experienced the Canterbury earthquake and those who didn't.

The specific aims of Phase Two were:

1. To quantify the findings of Phase One with a national sample of individuals who use wheelchairs using descriptive epidemiology and investigate associations between Phase One findings and level of exposure to the 2010/2011 earthquakes and subsequent length of stay in the greater Christchurch area;
2. to test a novel sampling approach, RDS, to access people who use wheelchairs, which had the potential to enable the calculation of unbiased population-based estimates that could be generalised to the target population.

5.3 Survey development

The development of the survey used in Phase Two was needed because there were no pre-established instruments designed to measure community inclusion for wheelchair users following natural disasters. The survey development process began by appraising each of the five themes from Phase One to assess which components were most important to be captured in the survey instrument. It was envisioned that each theme from Phase One would form the basis for a specific section of the survey. This assessment process involved two steps. First, I examined each theme in terms of how feasible it would be to operationalise the content into survey items. Next, a table was created, with a row designated to each of the five themes, to help identify the exact areas to focus on. This table had five columns that examined 1) the specific variable of focus (e.g. *age*), 2) the potential wording of items (e.g. '*When were you born?*'), 3) the most appropriate response options (e.g. *age groups* or *actual date of birth*), 4) the reason for including the item (*i.e. to understand demographic characteristics of participants*), and 5) the source of the item if adopted from another instrument.

During this stage, a number of considerations were taken into account. A primary consideration was the quantity and complexity of questions needed to capture each

theme. A balance was required between having enough items thought adequate to explore each construct, without creating too much burden for those completing the survey. A second consideration was the wording of questions and responses. For example, the wording of Likert scale responses, or whether branching was required if a participant responded yes or no to a question. A third consideration was the length of the survey. The time taken to complete the survey was ideally to be no longer than 30 minutes in an online environment, as Web-based surveys with a longer expected length are associated with reduced participation and completion rates (Galesic & Bosnjak, 2009).

A fourth, significant consideration was deciding which time points would potentially best reflect participants' experience of community inclusion over a certain time period. As has been mentioned, the majority of disability and disaster research has explored the immediate time period following a disaster, and the research in my thesis intended to explore longer-term recovery. As such, many of the questions in the survey asked participants to reflect on various aspects of their community inclusion experience at *three time points*: the six months prior to the first earthquake in September 2010 earthquake (time one), the six months following the first earthquake in September 2010 (time two), and during the last six months at time of survey completion (time three). The rationale behind time one was to provide baseline data prior to the earthquakes. The rationale for time two was to provide data regarding the acute phase following the earthquakes, and time three was intended to provide data regarding the longer-term experience following the earthquakes.

Preference was given to using items from other established measures, with available psychometric estimates. An extensive literature search was performed for instruments that might explore similar constructs to those identified in the themes. The only instrument considered to correspond closely with the constructs identified in the Phase One findings were the CERA Wellbeing Surveys (Canterbury Earthquake Recovery Authority, 2012, 2013a, 2013b, 2014a, 2014b, 2015b, 2015c). This successive cross-sectional survey was established to measure earthquake recovery progress and was administered approximately every six months between 2012 and 2015. These survey findings were intended to help CERA and the partner agencies (the Christchurch City Council, the Waimakariri District Council, the Selwyn District

Council, the Canterbury District Health Board, Ngāi Tahu, and the Natural Hazards Research Platform) understand evolving trends in community wellbeing, allowing such agencies to make informed decisions regarding resource allocation during the recovery of Christchurch (CERA, 2015). In addition to having items that explored similar constructs to those of Phase One, the final administration of the CERA Wellbeing Survey was conducted in October 2015, the same month in which I began sampling for the Phase Two survey. This provided a unique opportunity to compare and contrast data from the Phase Two survey with data from that CERA survey. Such a comparison could help to situate the experience of our sample of wheelchair users within the context of the wider Christchurch population. The specific items derived from CERA survey are described below (see section 5.3.2).

The survey development table progressed through several iterations to process the above considerations. Each iteration was circulated to my supervisors for comment and revised accordingly. For example, the initial idea that each theme would correspond to one section was revised: themes one and two were combined into section four: *community access* (see below), and themes four and five were combined into section five: *the future* (see below). Once consensus was reached regarding the wording of each item, and the item content and frequency, the first prototype survey with 43 items was designed and transferred into SurveyMonkey™ format. This prototype survey was then pilot tested. The development and pilot testing of the survey, was conducted in close consultation with my supervisors.

5.3.1 Pilot testing

Pilot testing was conducted using an electronic format (SurveyMonkey™) via two stages. First, my supervisors completed the survey and provided feedback on issues such as question order (e.g. reordering questions comparing time points from most recent to least recent), and practical issues (e.g. ensuring only one response could be selected per option on matrix table items). After revision, four individuals recruited through my personal network also completed the survey. Two of these individuals were happy with the survey and had no comments, and two provided feedback on issues such as wording (e.g. including the word ‘current’ in questions comparing time points, e.g. Q8, Q10, Q15, Q35, Q36), underlining key terms for emphasis (e.g. underlining the words ‘at the time of earthquake’ in questions comparing time points

in Q9, Q11), and response options (e.g. for Q17, changing ‘how many years have you used a wheelchair’ to ‘what year did you begin to use a wheelchair’ in order to account for those who might have used a wheelchair for less than a year). During the pilot testing, I also downloaded the data from Survey Monkey into MS Excel to check data parameters and to ensure the format was appropriate for the downloading and transferal process. I met with my primary supervisor (PS) to discuss and assess the pilot feedback. Once changes were made, the prototype survey underwent a final review by my supervisors and a final survey was prepared. This final version is the instrument used in Phase Two.

5.3.2 Final survey

The final survey consisted of six sections (see Appendix M). Section one focused on background information, section two on mobility information, section three on earthquake experience, section four on community access, section five on social connectedness, and the final section, section six, focused on the future. Response options varied including: multiple options (e.g. Q23 Were you present in the Christchurch district during any of the following earthquakes?), Likert scales (e.g. Q42 What impact has the Christchurch sequence of earthquakes had on you?), closed questions with dichotomous response options (e.g. Q25 Is Christchurch your place of residence?), and open responses (e.g. Q41 Do you have any other comments you would like to make regarding community inclusion following the Canterbury earthquakes?).

Section one: Background information

The first section included 11 items and was concerned with capturing socio-demographic information such as gender, age, ethnicity, income, housing situation (current and in September 2010), living arrangements (current and in September 2010), geographical location (current and in September 2010), and impact of earthquakes on housing situation. Questions on gender, ethnicity, income, and geographical location were worded in the same way as the CERA Wellbeing Survey for direct comparative purposes, age was worded in the same way as the 2013 Statistics New Zealand Census, and the remaining questions were derived de novo.

Section two: Mobility information

Section two included eight items focusing on the type of wheelchair used (current and in September 2010), when the respondent began using a wheelchair as their main form of mobility, the specific impairment that required the use of a wheelchair, whether the respondent required attendant care support (and if yes, how many hours per day), and whether the respondent received financial support because of their impairment (and if yes, the primary funder of that support). This information was considered important for the potential examination of associations between impairment related variables and community inclusion outcomes. One item (Q21) exploring funding was adapted from a recently completed doctoral survey instrument (Smaill, 2015).

Section three: Earthquake experience

Section three included seven items focusing on earthquake exposure in terms of whether the respondent was in Christchurch during any of the largest four earthquakes, the amount of time spent living in Canterbury in the five years since September 2010, whether Christchurch is the respondents primary place of residence (current and in September 2010), the respondents perceived quality of life, and whether this perceived quality of life had changed since September 2010. Items on quality of life (Q28 and Q29) were worded in the same way as the CERA Wellbeing Survey for comparative purposes.

Section four: Community access

The section named *Community Access* included four questions asking participants about their experience of community accessibility. Three questions focused on three different points in time: the six months prior to the first earthquake in September 2010 earthquake (time one), the six months following the first earthquake in September 2010 (time two), and the last six months at time of survey completion (time three). Each of the three questions listed 11 options (such as access to footpaths, housing, and workplaces; all of which were derived from theme one in Phase One). For each option participants could select six responses on a Likert scale: impossible, always hard, often hard, occasionally hard, never hard, and not applicable. A fourth question asked if accessibility had changed, and if so, why. Several options including a comment box were provided. No items in section four were taken from other sources.

Section five: Social connectedness

Section five included five items asking participants to rate their degree of sense of community with others in their neighbourhood at three points in time, namely: the six months prior the first earthquake in September 2010 earthquake (time one), the six months following the first earthquake in September 2010 (time two), and the last six months at time of survey completion (time three). Participants were also asked if they were faced with a serious injury or illness, whether they had people they could turn to in a time of need and if yes, who those people might be. The item on degree of sense of community with others in their neighbourhood was worded in the same way as the CERA Wellbeing Survey for comparative purposes.

Section six: The future

Section six included five items. The first item asked respondents to rate to what extent they felt there was an opportunity to improve accessibility in their community since September 2010, and whether this had increased, not changed, or decreased since the September 2010 earthquake. An item also asked participants to rate to what extent they felt confident that three stakeholders (council, government, and building developers) were making decisions in the best interests of rebuilding an accessible city. These questions were all derived directly from themes four and five in Phase One. The final two items asked participants to rate on a four-point Likert scale what overall impact the Canterbury earthquakes have had. The last item was an open comment box inviting any other comments regarding community inclusion following the Canterbury earthquakes.

5.4 Methods

With regard to aim one, my original intent was to conduct a ‘national survey’ of people who use wheelchairs. I wanted to reach two groups – those who had exposure to earthquakes, and those who did not, using a novel sampling approach, RDS.

5.5 Respondent-driven sampling

RDS appealed as the sampling method for Phase Two of this study due to the potential it provided to draw valid statistical inferences from a sample of people who use wheelchairs in New Zealand, even though no sampling frame existed to know if

that sample was representative (see section 2.4.1). RDS is initiated by recruiting a handful of individuals who serve as ‘seeds’ who, once having completed the survey then recruit peers to complete the same survey. However, unlike traditional snowball convenience sampling, RDS requires seeds and subsequent participants to provide their recruitment code (to keep track of the recruitment chains) and an estimate of their network size (the number of people a person knows in the target population) (Heckathorn, 1997). In this study this was evaluated by question two in the survey that asked, “Approximately how many other wheelchair users do you know?” These data are required for statistical analysis to determine if the sample reaches the point of equilibrium distribution (see section 5.5.4).

RDS is a chain referral type approach that can potentially produce a representative sample when no sampling frame exists (which is the case for wheelchair users in New Zealand) if certain assumptions are met. The two groups could then be compared with regard to the prevalence of the primary findings of Phase One. With the failure of RDS (see section 5.5), this original aim was revised to conduct a local survey of wheelchair users who lived only in Christchurch. The reporting of the survey methods in this chapter was informed by the guidelines for cross-sectional studies outlined by the Strengthening of Reporting of Observational Studies in Epidemiology (STROBE) initiative (von Elm et al., 2008).

5.5.1 Study design

Phase Two employed a current and retrospective cross-sectional electronic survey (administered electronically via SurveyMonkey™).

5.5.2 Participants

The target population was New Zealand adults who used wheelchairs as their main form of mobility. To be included, participants were required to:

1. use a wheelchair as their main form of mobility (defined through participants self-reporting wheelchairs as their main form of mobility);
2. reside in New Zealand;

3. be aged 16 years or older;
4. be able to read English; and,
5. have access to internet and have an operational email account⁶.

5.5.3 Sampling and recruitment

An email (Appendix N) describing the study was sent to various national disability organisations serving members with a range of impairments that lead to wheelchair use, such as CCS Disability, the Earthquake Disability Leadership Group, the NZ Cerebral Palsy Society, and the NZ Spinal Trust. All organisations were supportive of the study, and agreed to circulate invitations seeking ‘seed’ participants on my behalf. Physical invitations were also placed in libraries, hospitals, and tertiary education facilities in Christchurch. People expressing interest in being seeds contacted me, I confirmed eligibility via phone or email (depending on how potential seeds contacted me) and then sent seed participants a recruitment code and a link to the SurveyMonkey™ website.

Once a participant followed the link to the SurveyMonkey™ website, links were provided in the survey preamble to a detailed information sheet (Appendix O) and information video. It was hoped an information video would help to explain RDS and how if people chose to participate they would be asked to circulate recruitment codes to others in their network. Upon completion of the survey, participants were thanked and emailed three unique recruitment codes (Appendix P). The recruitment codes enabled tracing of the recruitment chains, a key requirement of RDS. The initial seed participants at the start of the chain were provided with an identifying letter (e.g. A, B, C). As the waves expanded, each participant received a code that comprised of their recruiter’s code followed by a suffix digit (1, 2, or 3). For example, participant ‘A1’ was asked to pass on the codes A11, A12, and A13. Participant ‘A11’ was asked to pass on A111, A112, and A113 and so on. Participant recruitment codes were

⁶ Access to the internet was required in order to complete the survey via SurveyMonkey.com, and an email address was required to receive recruitment codes to pass on to other participants. See recruitment section below for discussion on electronic delivery of the survey.

requested on the survey form (question 1), and kept in a participant identification database.

Participants were asked to email one code and the survey link to three other persons they knew who were likely to satisfy the eligibility criteria. This process was envisaged to continue for multiple recruitment waves. Recruitment chains were tracked through tracing the recruitment codes. If seeds or their three peers failed to complete the survey (established through the presence (or absence) of certain codes on the survey), reminder emails were sent to them after one and two weeks. No more reminders were sent after this, so as not to unnecessarily bother participants. This process continued for each wave of participants. If no responses were received for six consecutive weeks (to allow for the reminders at one and two weeks, plus four weeks grace for people who may have received codes to complete the survey), the survey would be closed.

A further requirement of RDS is the use of ‘dual incentives’, whereby “respondents are rewarded for both their participation, *and* the participation they elicit from a peer” (Heckathorn, 1997) (p.177). Participation in this study was incentivised (an entry into a draw to win an iPad); one entry for completing the survey, and another when each person they recruited completed the survey (confirmed through the participant recruitment code that participants were required to submit when they completed the survey). A maximum of three secondary entries could be received (one for each recruit), and when added to the initial primary entry, accumulated into a potential total of four entries in the draw to win the iPad (see section 5.6.5 for information regarding draw).

The use of internet-based surveys in epidemiology is increasing (Turner, Bain, Schluter, Yorkston, & Bogossian, 2009) and the 2013 census suggested 76% of homes in New Zealand have access to the internet (Statistics New Zealand, 2013). Consideration was given to using a postal survey as well, in light of the argument that people living with disability can have reduced access to computers and the internet (Dobransky & Hargittai, 2006). However with the unique design of RDS, this would involve sending every participant, including seeds, three physical copies of the survey, an information sheet, and return envelopes. With the potential for such a large amount of paperwork, using an electronic medium was considered to be more time

and cost-effective in terms of printing cost, labour, distribution, management, and burden on participants.

5.5.4 Results

Recruitment commenced on 28th October 2015 and twenty potential seeds contacted me over a two-month period, and from these, twelve seeds completed the survey, a 60% response rate. All 12 seeds were asked to recruit a maximum of three wheelchair users. Only four seeds were successful in recruiting further participants (three seeds each recruited two participants, and one seed recruited one participant), accumulating in a total of seven first wave participants. Despite all seven first wave participants being asked to recruit a maximum of three wheelchair users, no second wave participants completed the survey. Thus, a total of 19 participants completed the survey using the RDS sampling approach.

Mean age of participants was 55.6 years (range: 28–73 years), and nine were women. Eighteen identified as New Zealand European and one identified as New Zealand Māori. Reasons for using a wheelchair included impaired mobility resulting from spinal cord injury (n=10), cerebral palsy (n=2), spina bifida (n=2), muscular dystrophy (n=2), poliomyelitis (n=2), and arthritis (n=1). Survey completion time ranged between 7 and 36 minutes. The final participant during the RDS approach completed the survey on 9th December 2016. Zero responses were received for six consecutive weeks after this date and the survey closed on 20th January 2016.

Because only one wave was recruited, the assumptions needed to compute equilibrium (a critical requirement needed to calculate unbiased population-based estimates) were not achieved. Equilibrium is the state at which the sample is considered independent from the bias introduced from the initial seeds, thereby enabling the calculation of unbiased population estimates (Volz & Heckathorn, 2008). Equilibrium is reached when there is relatively little variation in the sample proportions of key characteristics (such as age or gender) between successive measurement waves. The threshold for variation tolerance is determined prior to RDS implementation and a value of 2% is commonly employed (Wejnert, 2009; World Health Organisation, 2013b). Equations for calculating equilibrium are described by Heckathorn (2002). Data produced before sampling equilibrium is reached are termed ‘out-of-equilibrium data’ and are normally discarded due to their inherent biases.

Unbiased population-based estimates use ‘in-equilibrium data’, data generated after equilibrium is reached, so that recruitment theoretically represents a random sample of network ties.

For this study, obtaining in-equilibrium data (the state at which the sample is considered independent from the bias introduced from the initial seeds, thereby enabling the calculation of unbiased population estimates) failed due to a recruitment chain of only one wave. Even in the best-case scenario where equilibrium was reached through one wave, no data was produced *after* sampling reached equilibrium. It is this in-equilibrium data that is required to conduct analysis that might yield estimates independent of the original seeds. Furthermore, when only a single wave is conducted, all participants are within a single link from the seed participants accessed by the researcher. Such a sample lacks what Heckathorn (2002, p. 19) describes as “sociometric depth” where such a sample would in all likelihood fail to be representative of the entire hidden population. For these reasons, an analysis to assess whether equilibrium was reached was considered unnecessary, as the likelihood that data were in-equilibrium, conceptually and statistically, was impossible.

5.6 Amended methods

Despite the failure of RDS to yield sufficient samples in earthquake exposed and non-exposed groups needed for my original aims, a small number of earthquake exposed people had responded. Instead of abandoning this important phase of the study, I decided to revise the aims, and re-scope the quantitative component, limiting it to people residing in Christchurch. However, as before, no readily available sample frame existed. As such, I resorted to a convenience sampling approach to bolster sample numbers. In doing so, it was recognised that the external validity of findings from this sample were likely to be diminished – but the hope was that internally valid results would still be derived. In moving to a convenience sampling approach, the geographical focus shifted from a national survey to Christchurch centric convenience sampling and aimed only to involve those affected by the earthquakes. This resulted in the abandonment of the original aim of comparing two groups based on earthquake exposure. Instead, I decided to focus on assessing the prevalence, and relationships between, the variables in a sample of people who were experiencing the recovery phase of Christchurch. For the convenience sampling approach, hard copies of the

survey were available on request in a further effort to potentially increase participation. The University of Canterbury's Human Ethics Committee approved this amendment (See Appendix Q).

5.6.1 Amended aims

With the failure of RDS (see section 5.5.4), the key question of Phase Two remained the same, however the initial specific aim was amended. My original intent to conduct a 'national survey' of people who use wheelchairs, was revised to conduct a local survey of wheelchair users who lived only in Christchurch.

As a result, the initial aim:

1. To quantify the findings of Phase One with a national sample of individuals who use wheelchairs using descriptive epidemiology and investigate associations between Phase One findings and level of exposure to the 2010/2011 earthquakes and subsequent length of stay in the greater Christchurch area;

was amended to:

1. To quantify the findings of Phase One with a regional sample of individuals who use wheelchairs using descriptive epidemiology to explore key proportions and patterns between variables

5.6.2 Study design

In Phase Two I employed a retrospective and current cross-sectional electronic and hard copy survey.

5.6.3 Participants

The target population was New Zealand adults who used wheelchairs as their main form of mobility and were residents of Christchurch. To be included, participants were required to:

1. use a wheelchair as their main form of mobility (defined through participants self-reporting wheelchairs as their main form of mobility);
2. reside in Christchurch, New Zealand;

3. be aged 16 years or older; and
4. be able to read English.

Exclusion criteria included:

1. having already completed the RDS survey;
2. having no earthquake exposure; and
3. residing outside of Christchurch, New Zealand.

5.6.4 Sampling and recruitment

Any new people recruited during the convenience sampling were added to those Christchurch residents who had completed the RDS survey. Participants who lived outside Christchurch and had completed the RDS survey were excluded from subsequent data analysis. For the convenience sampling a generic invitation was produced which explained the survey and included a link to the survey URL address (Appendix R). This invitation was distributed to my personal contacts, disability organisations (CCS disability, the Earthquake Disability Leadership Group, the NZ Cerebral Palsy Society, and the NZ Spinal Trust), and hard copy invitations were placed throughout the Christchurch community (in libraries, hospitals and tertiary education facilities). Once a participant followed the link to the SurveyMonkey™ website, the preamble included a link to a detailed information sheet. However, unlike the RDS stage, an information video was not included as the recruitment process did not require a detailed explanation: the information sheet was considered sufficient. The preamble also asked for participants to distribute the survey link to other wheelchair users they knew who might be interested in completing the survey.

The convenience sampling approach was different to the RDS approach in two further ways. First, a hard copy of the survey was made available. The survey invitation asked anyone wanting a hard copy to contact me and I sent a hardcopy survey, an information sheet, and a pre-paid self-addressed envelope to return the survey. Second, participants responding to the convenience sample were not offered a dual incentive. Instead, potential participants received one entry into the iPad draw when they completed the survey, but no additional entry for participants they recruited. This was primarily the consequence of there being no recruitment codes required during convenience sampling. As a consequence I did not know who recruited whom. The

survey was opened on 22nd January 2016 and due to the reducing number and frequency of respondents, was closed on the 20th March 2016.

5.6.5 Data management

Data submitted in the survey was kept private and secure. SurveyMonkey™ uses software such as Norton, McAfee, TRUSTe, and the Better Business Bureau to keep all data secure. In the RDS, seeds and participants were known only via their identification code (to monitor recruitment networks) and their email address (needed in order to provide recruitment codes for them to recruit, and for notification if they won the iPad draw). In the convenience sample, participants were known by their email addresses. The email addresses were kept on a password protected database and were only able to be accessed by myself. A second, completely separate research database held numerical data, such as the participant identification codes and survey responses. A research assistant was used to help with data cleaning and only had access to this, de-identified research database.

To ensure transparency, the draw to win the iPad was conducted on 23th June 2016 at a public event: the Burwood Academy of Independent Living's bimonthly peer group meeting. This meeting is a lunchtime event in which researchers present their work to other researchers, clinicians, and colleagues at Burwood Hospital, Christchurch, New Zealand. Prior to the meeting the email addresses of participants were assigned a number. These numbers were included in a container. At the start of the meeting, prior to the presentations, a staff member from the Burwood Academy drew a number from the vessel and held it up to show the audience. A thesis supervisor was present and confirmed with me the match of number and email address. I then contacted with the winner via to arrange delivery of the iPad.

5.6.6 Data analysis

Data were initially managed through downloading the raw SurveyMonkey™ file into Microsoft's Excel spreadsheet. After the research database was created, stripping away identifying fields and information, data were then checked for missing, out of range, or duplicate values and corrected where possible. Variables and values were labelled and re-classified for statistical manipulation. This database was then imported into the specialist statistical software Statistical Package for the Social Sciences (IBM

SPSS version 23.0) and Stata (StataCorp version 14.2) for analysis. Descriptive analyses included frequency distributions, and estimates of location and spread. Bivariable comparisons included correlation analyses, and scatterplots for global community access scores. The strength of any correlation coefficients were determined using the following thresholds: <0.01 = none; $0.01-0.29$ = weak; $0.30-0.69$ = moderate; $0.70-0.99$ = strong; >0.99 = perfect (Coolican, 2004). Particular subgroups considered in bivariable comparisons included gender, age, ethnicity, mobility type, impairment and funding.

For matched data, statistical comparisons between groups used McNemar's and Student's paired t-tests for categorical and continuous variables, respectively. For independent comparisons between groups, Fisher's exact and Student's t-tests were employed. Change over time data involving continuous data were corrected for the possibility of the regression-to-the-mean effect, which occurs when unusually large or small measurements are followed by measurements that are closer to the mean, making natural variation in repeated data look like a real change (Barnett, van der Pols, & Dobson, 2005). The significance level for all tests was set at $\alpha=0.05$.

A standardised global community access score, with a range between $[0, 1]$, was calculated from 10 individual community access score items for each participant to enable comparison and analysis of reported community accessibility. The value of a participant's global community access score was the sum of each participant's response option for each community access item (0=impossible, 1=always hard, 2=often hard, 3=occasionally hard, and 4=never hard), for the ten access options listed in survey questions 28, 29, and 30. It was anticipated that participants might not select a response for every access item. Therefore, it was decided *a priori* that a respondent must have selected at least six responses to the ten constitute variables. The standardised score was derived by summing the value of each question, and then dividing by the number of valid question responses multiplied by 4.

5.7 Results (post recruitment amendment)

5.7.1 Participant profile

Combining the participants from the RDS and the convenience sample, 75 survey responses were collected. Eleven ineligible survey responses were identified during

the data cleaning process. These included six people (four during RDS sampling, and two recruited during convenience sampling) who had no earthquake exposure and were outside of Christchurch. There were also four duplicate entries, and one entry was excluded because it came from the parent of a wheelchair user whom was under the age of 16 years. This resulted in a final sample of 64 people, with 15 (23%) being recruited using RDS sampling, and 49 (77%) being recruited using convenience sampling.

Sixty participants (94%) completed the survey electronically, and four (6%) completed hardcopy versions. Table 5.1 summarises the key demographic characteristics of the participants. Mean age of participants was 50.5 years (range: 16, 82 years), and mean time spent using a wheelchair was 21.0 years (SD = 12.6, range: 1, 54 years). Thirty-nine (61%) identified as male and 57 (89%) identified as New Zealand European with six (9%) identifying as New Zealand Māori. In terms of mobility, participants reported a variety of impairments that required them to use a wheelchair, the two most common being spinal cord injury (n=38, 59%) and cerebral palsy (n=10, 16%). Three (5%) participants reported that in addition to using a wheelchair they sometimes used a walking frame, used a scooter, or walked respectively.

Table 5.1. Participant demographic and mobility characteristics (N=64)

| Variable | n (%) |
|--|---------|
| <i>Age (years)^a</i> | |
| ≤50 | 29 (45) |
| >50 | 34 (53) |
| <i>Gender</i> | |
| Male | 39 (61) |
| Female | 25 (39) |
| <i>Ethnicity^b</i> | |
| New Zealand European | 57 (89) |
| New Zealand Māori | 6 (9) |
| Pacifica | 2 (3) |
| Other | 3 (5) |
| <i>Income^c</i> | |
| No income | 2 (3) |
| Less than \$30,000 | 20 (31) |
| \$30,001-\$100,000 | 16 (25) |
| More than \$100,000 | 8 (13) |
| Don't know | 7 (11) |
| Prefer not to say | 9 (14) |
| <i>Impairment^d</i> | |
| Spinal cord injury | 38 (59) |
| Cerebral Palsy | 10 (16) |
| Multiple Sclerosis | 1 (2) |
| Spina bifida | 3 (5) |
| Muscular dystrophy | 3 (5) |
| Traumatic brain injury | 1 (2) |
| Other | 9 (14) |
| <i>Mobility^e</i> | |
| Manual wheelchair | 26 (41) |
| Power wheelchair | 22 (34) |
| A mix of both | 11 (17) |
| Other | 3 (5) |
| <i>Time using a wheelchair (years)^f</i> | |
| 0-19 | 26 (41) |
| 20-39 | 28 (44) |
| 40+ | 6 (9) |
| <i>Funding provider^g</i> | |
| ACC ^g | 25 (39) |
| MOH ^h | 22 (34) |
| Other | 4 (6) |

Notes: ^a 1 value missing; ^b Multiple responses possible; ^c 2 (3.1%) values missing; ^d 2 (3.1%) values missing; ^e 2 (3.1%) values missing; ^f 4 (6.3%) values missing; ^g 13 (20.3%) values missing.

5.7.2 Reported community access

Table 5.2 and Figure 5.1 present the distribution of participant responses for each community access item across the three different time periods. Table 5.2 gives the distribution of the five response options where Figure 5.1 shows the percentage of participants who reported substantial difficulty accessing certain areas of the community at the three different time periods. Here, substantial difficulty incorporated the response options 'impossible', 'always hard' and 'often hard' while the minimal difficulty category incorporated 'occasionally hard' and 'never hard'. The rationale for incorporating the response options into dichotomous variables was to aid analysis and provide clarity to the interpretation. From Figure 5.1 it can be seen that for all access items, participants reported that substantial difficulty was lowest for the six months prior to the September 2010 earthquake (time one), but then rose sharply at six months following September 2010 earthquake (time two), and reduced slightly during the last six months at time of survey completion (time three), although this remained higher than time one.

Table 5.2. Distribution of perceived difficulty for community access over all three time periods (N=64).

| Access area | Time period ^a | Substantial difficulty | | Minimal difficulty | | | N/A | Missing |
|--|--------------------------|------------------------|-------------|--------------------|-----------|------------|-----|---------|
| | | Impossible | Always hard | Often hard | Occ. hard | Never hard | | |
| | | n (%) | n (%) | n (%) | n (%) | n (%) | | |
| Access footpaths due to uneven surfaces | Time One | 0 (0.0) | 22 (39.3) | 7 (12.5) | 27 (48.2) | 0 (0.0) | 3 | 5 |
| | Time Two | 10 (18.2) | 15 (27.3) | 18 (32.7) | 11 (20.0) | 1 (1.8) | 2 | 7 |
| | Time Three | 3 (5.2) | 13 (22.4) | 23 (39.7) | 19 (32.8) | 0 (0.0) | 1 | 5 |
| Access footpaths due to repair and construction work | Time One | 3 (5.7) | 0 (0.0) | 5 (9.4) | 22 (41.5) | 23 (43.4) | 5 | 6 |
| | Time Two | 10 (18.5) | 12 (22.2) | 18 (33.3) | 11 (20.4) | 3 (5.6) | 2 | 8 |
| | Time Three | 6 (10.3) | 10 (17.2) | 20 (34.5) | 21 (36.2) | 1 (1.7) | 1 | 5 |
| Find suitable accessible housing | Time One | 2 (10.5) | 3 (15.8) | 4 (21.1) | 5 (26.3) | 5 (26.3) | 39 | 6 |
| | Time Two | 7 (36.8) | 6 (31.6) | 4 (21.1) | 1 (5.3) | 1 (5.3) | 37 | 8 |
| | Time Three | 3 (16.7) | 7 (38.9) | 4 (22.2) | 2 (11.1) | 2 (11.1) | 39 | 7 |
| Find accessible places for social interactions | Time One | 2 (3.7) | 1 (1.9) | 3 (5.6) | 19 (35.2) | 29 (53.7) | 4 | 6 |
| | Time Two | 5 (9.8) | 10 (19.6) | 15 (29.4) | 14 (27.5) | 7 (13.7) | 5 | 8 |
| | Time Three | 2 (3.7) | 7 (13.0) | 16 (29.6) | 22 (40.7) | 7 (13.0) | 4 | 6 |
| Access your workplace | Time One | 0 (0.0) | 0 (0.0) | 1 (3.3) | 2 (6.7) | 27 (90.0) | 27 | 7 |
| | Time Two | 2 (8.0) | 4 (16.0) | 6 (24.0) | 6 (24.0) | 7 (28.0) | 30 | 9 |
| | Time Three | 1 (3.3) | 1 (3.3) | 3 (10.0) | 13 (43.3) | 12 (40.0) | 28 | 6 |
| Access your | Time One | 0 (0.0) | 0 (0.0) | 1 (8.3) | 3 (25.0) | 8 (66.7) | 46 | 6 |

| | | | | | | | | |
|--|------------|----------|-----------|-----------|-----------|-----------|-----|-----|
| education centre | Time Two | 2 (15.4) | 2 (15.4) | 4 (30.8) | 4 (30.8) | 1 (7.7) | 42 | 9 |
| | Time Three | 0 (0.0) | 2 (13.3) | 2 (13.3) | 8 (53.3) | 3 (20.0) | 43 | 6 |
| Receive attendant care services | Time One | 0 (0.0) | 0 (0.0) | 4 (10.3) | 9 (23.1) | 26 (66.7) | 18 | 7 |
| | Time Two | 1 (2.6) | 2 (5.3) | 6 (15.8) | 12 (31.6) | 17 (44.7) | 16 | 10 |
| | Time Three | 2 (5.0) | 1 (2.5) | 4 (10.0) | 17 (42.5) | 16 (40.0) | 18 | 6 |
| Find accessible car parks | Time One | 2 (4.0) | 2 (4.0) | 6 (12.0) | 25 (50.0) | 15 (30.0) | 7 | 7 |
| | Time Two | 4 (8.5) | 7 (14.9) | 21 (44.7) | 13 (27.7) | 2 (4.3) | 8 | 9 |
| | Time Three | 2 (3.9) | 5 (9.8) | 22 (43.1) | 17 (33.3) | 5 (9.8) | 8 | 5 |
| Gain entry to, and move inside, buildings built pre-quake | Time One | 1 (1.8) | 1 (1.8) | 9 (16.1) | 36 (64.3) | 9 (16.1) | 2 | 6 |
| | Time Two | 4 (7.5) | 16 (30.2) | 14 (26.4) | 16 (30.2) | 3 (5.7) | 2 | 9 |
| | Time Three | 2 (3.4) | 5 (8.5) | 21 (35.6) | 28 (47.3) | 3 (5.1) | 0 | 5 |
| Gain entry to, and move inside, buildings built post-quake | Time One | N/A | N/A | N/A | N/A | N/A | N/A | N/A |
| | Time Two | 2 (4.1) | 8 (16.3) | 15 (30.6) | 16 (32.7) | 8 (16.3) | 7 | 8 |
| | Time Three | 2 (3.4) | 4 (6.9) | 17 (29.3) | 22 (37.9) | 13 (22.4) | 0 | 6 |
| Access public spaces in your community | Time One | 1 (1.8) | 1 (1.8) | 8 (14.3) | 32 (57.1) | 14 (25.0) | 2 | 6 |
| | Time Two | 2 (3.7) | 7 (13.0) | 20 (37.0) | 21 (38.9) | 4 (7.4) | 2 | 8 |
| | Time Three | 1 (1.7) | 6 (10.3) | 14 (24.1) | 31 (53.4) | 6 (10.3) | 0 | 6 |

Notes: ^aTime one (six months prior September 2010 earthquake), time two (six months following September 2010 earthquake), time three (last six months at time of survey completion).

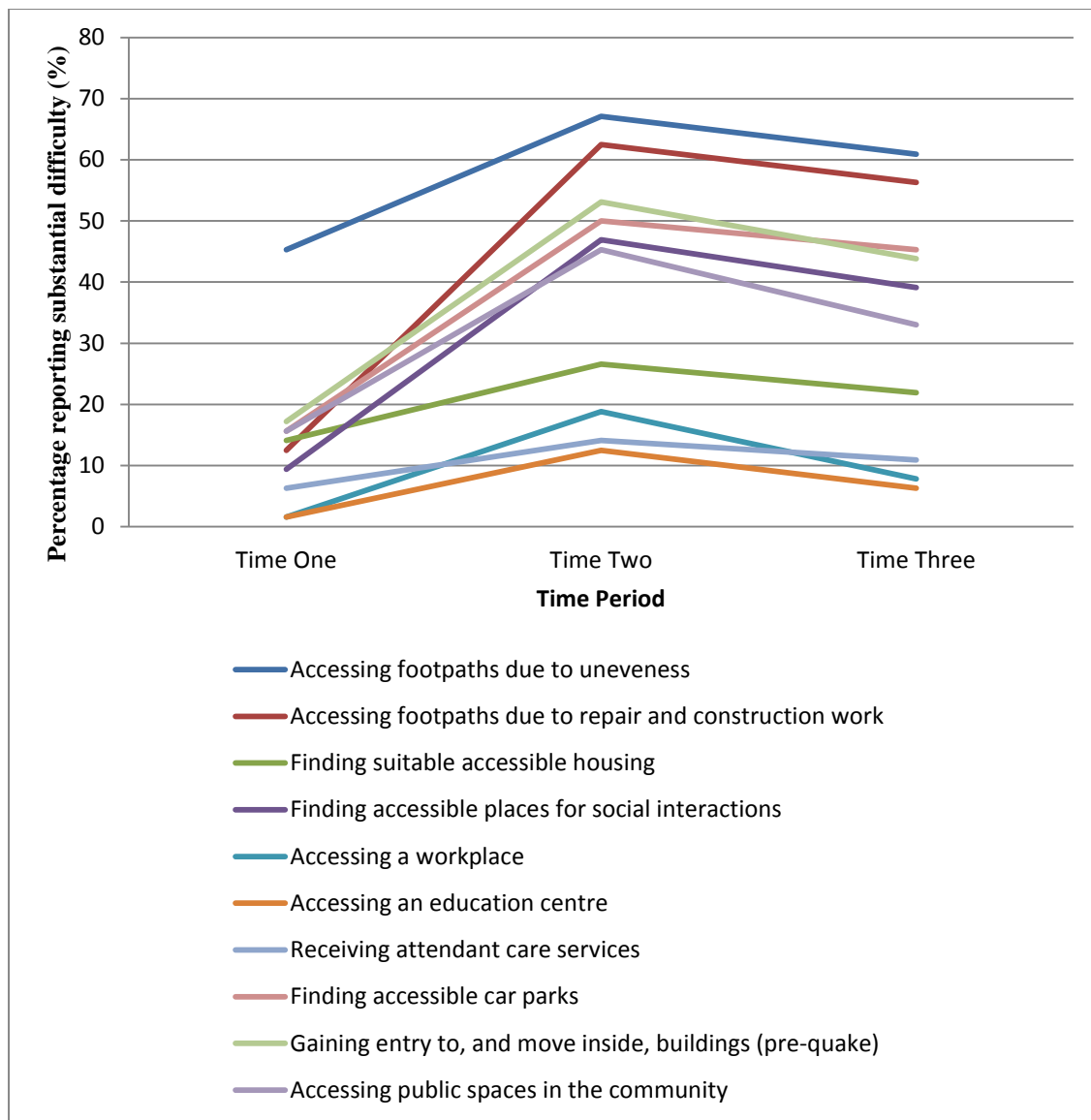


Figure 5.1. Percentage of participants who reported substantial difficulty accessing certain areas of the community at three different time periods (N=64).

Note: time one: the six months prior to the first earthquake in September 2010 earthquake; time two: the six months following the first earthquake in September 2010; time three: the last six months at time of survey completion.

Differences in reported difficulty of community access between the six months prior to the first earthquake in September 2010 earthquake (time one), the six months following the first earthquake in September 2010 (time two).

McNemar's test was used to determine whether there was a significant asymmetry between the levels of difficulty participants reported regarding community accessibility at time one and time two. This analysis could help to understand whether there was any change in the

difficulty of community access between the baseline time period (time one: the six months prior to the September 2010 earthquake), and the acute time period (time two: the six months following the September 2010 earthquake). The data indicate that there was a greater number of participants who reported *minimal difficulty* for time one, and *substantial difficulty* for time two; compared with the proportion of participants who reported *substantial difficulty* for time one, and *minimal difficulty* in all ten access items. Statistical asymmetry was observed in nine of the ten access items, including accessing footpaths due to uneven surfaces ($p=0.009$); accessing footpaths due to repair and construction work ($p<0.001$); finding suitable accessible housing ($p=0.02$); finding accessible places for social interactions ($p<0.001$); accessing a workplace ($p=0.002$); accessing an education centre ($p=0.03$); finding accessible car parks ($p<0.001$); gaining entry to, and moving inside, buildings (built pre-quake) ($p<0.001$); and, access to public spaces in the community ($p<0.001$). Only for the community access variable 'receiving attendant care services' was there no significant change ($p=0.13$). These data indicate a pattern that community access increased in difficulty in almost all of the access items measured in the survey between the time period prior to the September 2010 earthquake, and the time period following the September 2010 earthquake.

Differences in reported difficulty of community access between the six months prior to the first earthquake in September 2010 earthquake (time one) and the last six months at time of survey completion (time three).

McNemar's test was also used to determine whether there was a significant asymmetry between the levels of difficulty regarding community accessibility at time one and time three. This analysis could provide insight into any change between the difficulty of community access during the baseline time period (time one: the six months prior to the September 2010 earthquake), and the longer-term time period (time three: the last six months at time of survey completion). The data indicated that a greater number of participants reported *minimal difficulty* for time one, and *substantial difficulty* for time three; compared with the proportion of participants who reported *substantial difficulty* for time one, and *minimal difficulty* for time three. Five out of the ten items were observed as having statistical asymmetry including: accessing footpaths due to repair and construction work ($p<0.001$), finding accessible places for social interactions ($p<0.001$), finding accessible car parks ($p<0.001$), and gaining entry to, and moving inside, buildings (built pre-quake) ($p=0.004$), and access to public spaces in the community ($p=0.04$). The five items for which no significant asymmetry was observed

included accessing a workplace ($p=0.25$); accessing footpaths due to uneven surfaces ($p=0.57$); finding suitable accessible housing ($p=0.63$); accessing an education centre ($p=0.50$); and receiving attendant care services ($p=0.63$). These data signify that while the number of access items had reduced from nine to five (when compared to the above comparison between time one and time two), participants were still experiencing difficulty in accessing fifty per cent of the community items measured in the survey between time one (six months prior to the September 2010 earthquake), and time three (the last six months at time of survey completion).

Differences in reported difficulty of community access between the six months following the first earthquake in September 2010 (time two), and during the last six months at time of survey completion (time three).

McNemar's test was used to determine whether there was a significant asymmetry between the response profiles at time two and time three. This analysis could provide insight into any change between the difficulty of community access during the acute time period (time two: the six months following the September 2010 earthquake), and the longer-term time period (time three: the last six months at time of survey completion). A greater proportion of participants reported *minimal difficulty* for time three, and *substantial difficulty* for time two; compared with the proportion of participants who reported *substantial difficulty* for time three, and *minimal difficulty* for time two. Three out of the ten items were observed as having statistical asymmetry. These access items included accessing a workplace ($p=0.03$), gaining entry to, and moving inside, buildings (built pre-quake) ($p=0.007$), and access public spaces in the community ($p=0.004$). The seven items for which no significant asymmetry was observed included accessing footpaths due to uneven surfaces ($p=0.12$); accessing footpaths due to repair and construction work ($p=0.77$); finding accessible car parks ($p=0.65$); finding accessible places for social interactions ($p=0.09$); finding suitable accessible housing ($p=0.99$); accessing an education centre ($p=0.63$); and receiving attendant care services ($p=0.38$). These data indicate that there was little change in the degree of difficulty accessing community items between time two and time three, signifying that participants had experienced similar levels of difficulty accessing community between the acute time period (time two: the six months following the September 2010 earthquake), and the longer-term time period (time three: the last six months at time of survey completion).

Global community access scores

In a further attempt to quantify participants' experience of community accessibility, a standardised global community access score was calculated to enable comparison of reported community accessibility within and between time periods (see section 5.6.6). Initially, in creating the global community access scores, a correlation matrix was computed to examine the relationship between each of the access items within each time period. This was a necessary step. Because the global community access score was to be calculated using the items, it was essential to ascertain whether the community access items appeared to be related to validate using the global community access score. Table 5.3 presents the correlation coefficient values between access items for the time period six months following the first earthquake in September 2010 (time two).

Table 5.3. Correlation coefficient values between community access items six months following the first earthquake in September 2010 (time two) (N=64).

| | Footpaths (uneven) | Footpaths (repair) | Housing | Social interactions | Workplace | Education centre | Attendant care services | Car parks | Entry and access in buildings | Public places |
|----------------------------------|-----------------------|-----------------------|---------|------------------------|-----------|---------------------|-------------------------------|-----------|-------------------------------------|------------------|
| Footpaths (uneven) | 1 | | | | | | | | | |
| Footpaths (repair) | 0.93 | 1 | | | | | | | | |
| Housing | 0.26 | 0.26 | 1 | | | | | | | |
| Social interactions | 0.57 | 0.63 | 0.26 | 1 | | | | | | |
| Workplace | 0.16 | 0.18 | 0.27 | 0.25 | 1 | | | | | |
| Education centre | 0.20 | 0.22 | 0.23 | 0.28 | 0.42 | 1 | | | | |
| Attendant care services | 0.21 | 0.26 | 0.27 | 0.36 | 0.20 | 0.37 | 1 | | | |
| Car parks | 0.45 | 0.42 | 0.13 | 0.52 | 0.05 | 0.07 | 0.08 | 1 | | |
| Entry and access in buildings | 0.68 | 0.70 | 0.17 | 0.63 | 0.16 | 0.30 | 0.05 | 0.48 | 1 | |
| Public places | 0.58 | 0.60 | -0.01 | 0.56 | 0.18 | 0.38 | 0.17 | 0.41 | 0.75 | 1 |

Notes: Significance levels were not reported here as the primarily interest was in effect sizes rather than statistical significance.

The mean correlation coefficient value for six months following the first earthquake in September 2010 (time two) was $r=0.34$ (range: -0.01, 0.93). The correlation coefficient matrix distribution for the other two time periods were similar to those presented in Table 5.3. The mean correlation coefficient value for the six months prior to the first earthquake in September 2010 (time one) was $r=0.29$ (range: -0.27, 0.85) and during the last six months at time of survey completion (time three) was $r=0.29$ (range: -0.12, 0.86). A positive and moderate relationship between the different access domains is encouraging as it suggests that the items are related, but represent different aspects of the community access domain without a high degree of unnecessary redundancy that would be indicated if they were all highly correlated.

A further step in creating the global access score was deciding how many response options out of the ten must have been selected. Deciding on a threshold of selected responses was important as balance was required between ensuring enough responses were completed to validate the calculation of a global community access score, and not excluding too many participants if there were a large proportion that did not complete all ten response options. With these considerations in mind, it was decided *a priori* that global community access scores would be calculated using those participants who selected six or more responses from the ten constitute variables.

Table 5.4 outlines the distribution of participant responses for the ten response options, for all three time periods: the six months prior to the first earthquake in September 2010 earthquake (time one), the six months following the first earthquake in September 2010 (time two), and during the last six months at time of survey completion (time three). The majority of participants had six or more responses for all three time periods (85% for time one, 81% for time two, and 86% for time three).

Table 5.4. Distribution of non-missing responses over all ten community access variables (N=64).

| Number of response options selected | Time one n (%) | Time two n (%) | Time three n (%) |
|--|-------------------|-------------------|---------------------|
| 0 | 8 (13) | 9 (14) | 5 (8) |
| 1 | 0 (0) | 0 (0.0) | 0 (0) |
| 2 | 0 (0) | 0 (0) | 1 (2) |
| 3 | 0 (0) | 0 (0) | 0 (0) |
| 4 | 1 (2) | 2 (3) | 1 (2) |
| 5 | 1(2) | 1(2) | 2 (3) |
| 6 | 7 (11) | 7 (11) | 9 (14) |
| 7 | 19 (30) | 20 (31) | 18 (28) |
| 8 | 14 (22) | 10 (16) | 12 (19) |
| 9 | 9 (14) | 9 (14) | 10 (16) |
| 10 | 5 (8) | 6 (9) | 6 (9) |
| Total n (≥ 6 responses) ^a | 54 (84) | 52 (81) | 55 (86) |

Notes: ^aGlobal community access scores were calculated using those participants who selected six or more responses from the ten constitute variables.

Time one: the six months prior to the first earthquake in September 2010 earthquake; time two: the six months following the first earthquake in September 2010; time three: the last six months at time of survey completion.

Global community access scores between time periods

Following the correlation matrix and observing the response distributions, a standardised global community access score was calculated for each participant, for each time period. The global community access score had a range between [0, 1], and a higher score indicating a greater level of reported community access. Figure 5.2 presents a scatterplot of standardised global community access scores for the six months prior to the first earthquake in September 2010 (time one), and the six months following the first earthquake in September 2010 (time two). The majority of observations are located on the right-hand side (time one) of the superimposed line of equivalence, indicating that community access was the least difficult during time one when compared to time two.

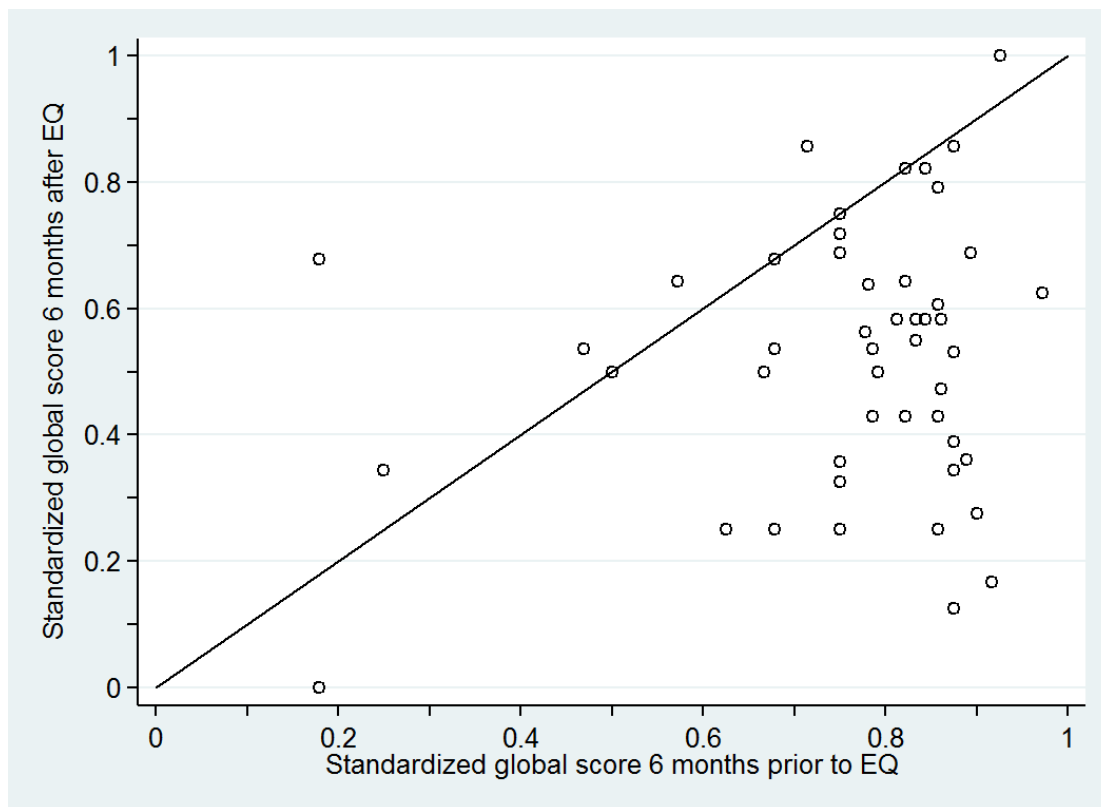


Figure 5.2. Scatterplot of standardised global community access scores for the six months prior to the first earthquake in September 2010 earthquake (time one), and the six months following the first earthquake in September 2010 (time two), together with a superimposed line of equivalence.

Notes. EQ stands for 2010 September earthquake.

A scatterplot (Figure 5.3) presents the standardised global community access scores for the six months prior to the first earthquake in September 2010 earthquake (time one), and during the last six months at time of survey completion (time three). These data indicate that community access was least difficult during time one when compared to time three, by virtue of the majority of observations being located on the right-hand side (time one) of the superimposed line of equivalence.

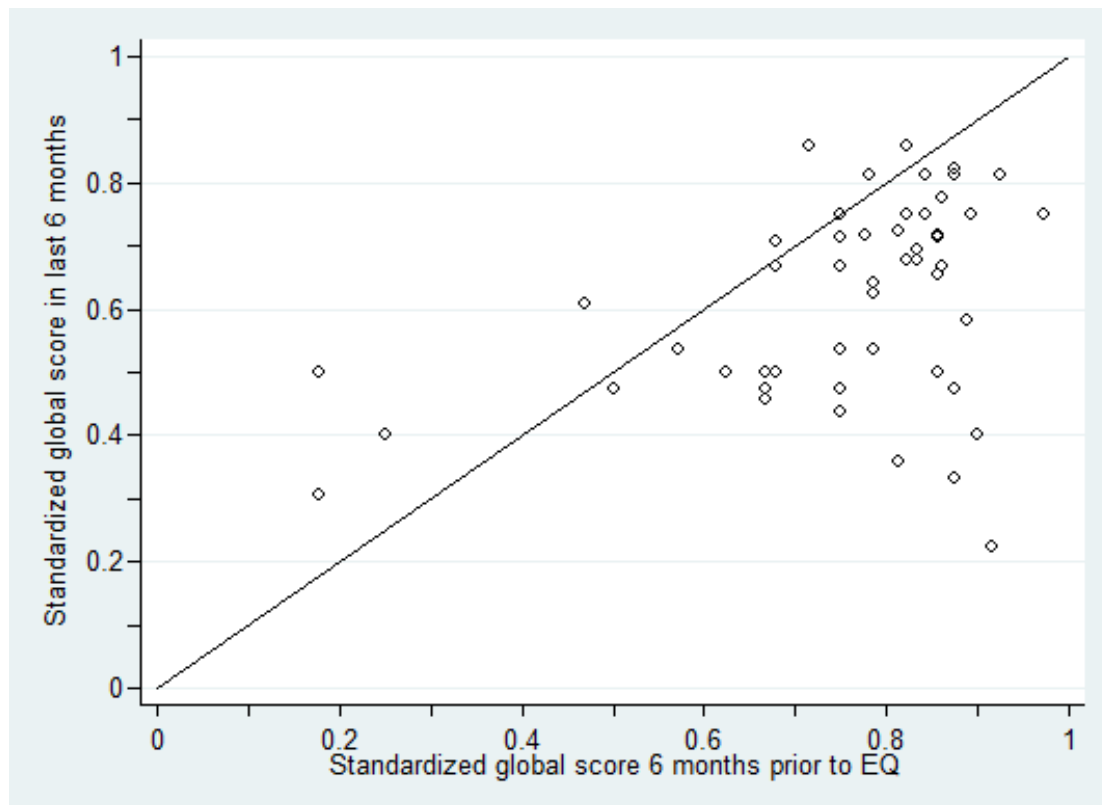


Figure 5.3. Scatterplot of standardised global community access scores for the six months prior to the first earthquake in September 2010 earthquake (time one), and during the last six months at time of survey completion (time three), together with a superimposed line of equivalence.

Notes. EQ stands for 2010 September earthquake.

A third scatter plot (Figure 5.4) presents the standardised global community access scores for the six months following the first earthquake in September 2010 (time two), and during the last six months at time of survey completion (time three). The majority of observations are located on the left-hand side (time three) of the superimposed line of equivalence, indicating that community access was the least difficult during time three when compared with time two.

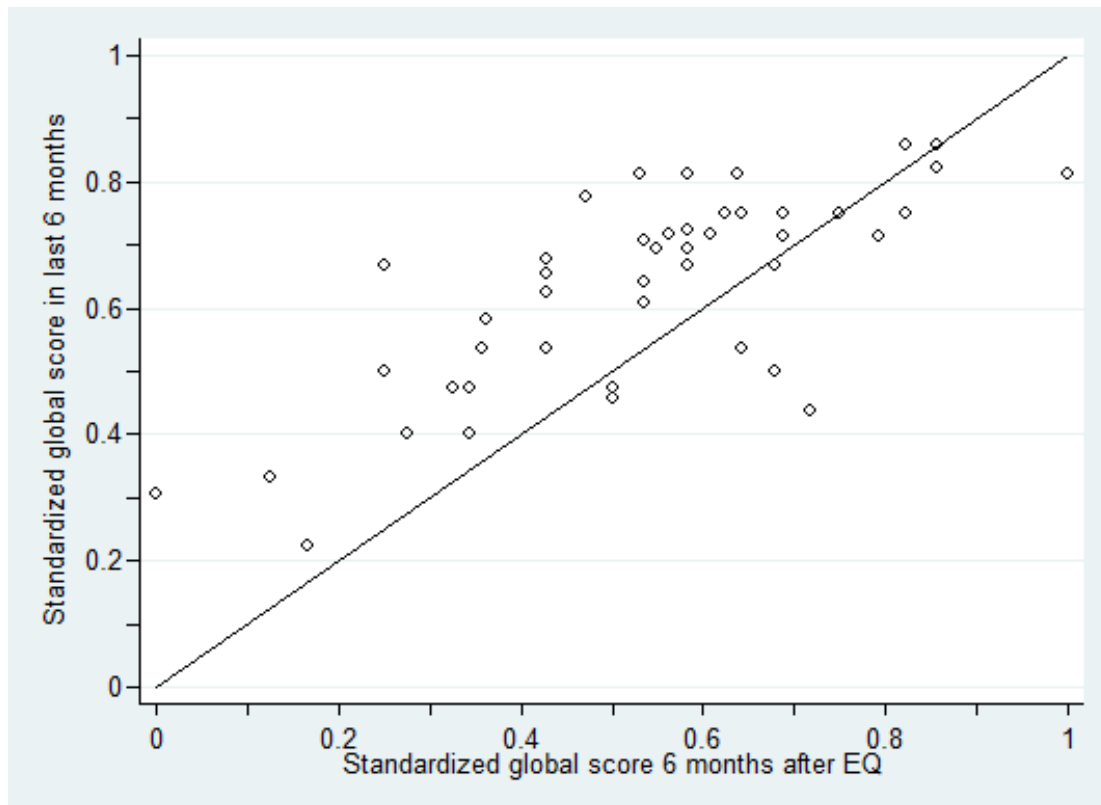


Figure 5.4. Scatterplot of standardised global community access scores for the six months following the first earthquake in September 2010 (time two), and during the last six months at time of survey completion (time three), together with a superimposed line of equivalence. Notes. EQ stands for 2010 September earthquake.

To further aid interpretation of the global access scores, student's paired t-tests were conducted to observe for significant differences between the mean global access scores over pair-wise time periods⁷. The mean global access score for time two ($M=0.52$, $SD=0.21$) was significantly lower compared with the mean global access score for time one ($M=0.75$, $SD=0.17$), a statistically significant decrease of 0.23 (95% CI: 0.16, 0.30; $t(50)=6.75$, $p<0.001$). The mean global access score for time three ($M=0.62$, $SD=0.15$) was also significantly lower compared with the mean global access score for time one ($M=0.75$, $SD=0.17$), a statistically significant decrease of 0.13 (95% CI: 0.08, 0.18; $t(51)=5.33$,

⁷ An assumption of paired t-tests is that participants are present in both groups. Fifty-one participants responded to ≥ 6 options in both time one and time two; $n=52$ participants responded to ≥ 6 options in both time one and time three, and $n=49$ participants responded to ≥ 6 options in both time two and time three. This variation altered the mean values when comparing the global access score between time three and time two.

$p < 0.001$). Finally, the mean global access score for time three ($M = 0.63$, $SD = 0.15$) was significantly higher compared with the mean global access score time two ($M = 0.53$, $SD = 0.21$), a statistically significant increase of 0.10 (95% CI: 0.06, 0.14; $t(48) = 4.87$, $p < 0.001$).

These data indicate that mean global access score for the acute time period (time two) and the longer-term time period (time three) were both significantly lower than the pre-earthquake baseline time period (time one: the six months prior to the first earthquake in September 2010 earthquake). This suggests that community access was most difficult for participants during the acute time period (time two), and while improving somewhat during the longer-term time period (time three), was still difficult for participants; and had not returned to the levels reported for the pre-earthquake baseline time period (time one).

Global community access scores between subgroups

I was also interested as to whether there was variation in the global community access score between subgroups of my sample. Student t-tests were conducted to observe whether gender, age, ethnicity, impairment, current mode of mobility, and funding accounted for any significant difference in global community access scores *within* each time period (Table 5.5). Variables with more than two levels were categorised into dichotomous variables to enable clarity during the interpretation. Ethnicity and impairment were dichotomised according to the response options that received the highest number of responses: New Zealand European and SCI respectively. The remaining response options in these variables were categorised as 'other'. Mobility was dichotomised according to the response option that received the highest number of responses: manual wheelchairs, and the categories 'power wheelchair' and 'a mix of both' were incorporated into the category 'Manual/power'. To reduce the chance of unusually large or small measurements skewing the analysis, statistical methods were employed to account for the possibility of regression to the mean, which occurs when unusually high or low measurements in repeated data can look like a real change (Barnett et al., 2005).

Gender accounted for a significant difference in global community access scores within time period three, but not within time periods one or two. For the last six months at time of survey completion (time three), participants identifying as female ($M = 0.55$, $SD = 0.15$) had a significantly lower global community access score than participants identifying as male

($M=0.66$, $SD=0.15$), a statistically significant decrease of 0.09 (95% CI: 0.01, 0.17; $t(49)=2.35$, $p=0.03$). Impairment accounted for a significant difference in global community access scores within time periods two and three respectively. For the six months following the first earthquake in September 2010 (time two), participants reporting a SCI had a significantly higher global community access score ($M=0.58$, $SD=0.19$) than the group reporting other impairments ($M=0.43$, $SD=0.23$), a statistically significant decrease of 0.14 (95% CI: 0.02, 0.25; $t(48)=2.29$, $p=0.03$). Likewise, for the last six months at time of survey completion (time three), participants reporting a SCI had a significant higher global community access score ($M=0.66$, $SD=0.13$) than the group reporting other impairments ($M=0.53$, $SD=0.17$), a statistically significant decrease of 0.12 (95% CI: 0.04, 0.20; $t(49)=3.08$, $p=0.003$). There were no significant differences in participants' global community access scores on the basis of age, ethnicity, current mode of mobility, and funding within each time period.

Table 5.5. Global community access scores between subgroups within each time period.

| | Time One n, mean (SD) | Time Two n, mean (SD) | Time Three n, mean (SD) |
|--------------------|--------------------------|--------------------------|----------------------------|
| <i>Gender</i> | | | |
| Male | 33, 0.77 (0.18) | 33, 0.56 (0.19) | 33, 0.66 (0.15) |
| Female | 21, 0.73 (0.16) | 19, 0.45 (0.22) | 22, 0.55 (0.15) |
| <i>Age (years)</i> | | | |
| ≤50 | 28, 0.73 (0.21) | 27, 0.52 (0.24) | 28, 0.62 (0.17) |
| >50 | 25, 0.78 (0.11) | 24, 0.52 (0.18) | 26, 0.60 (0.14) |
| <i>Ethnicity</i> | | | |
| NZ European | 46, 0.74 (0.18) | 44, 0.51 (0.21) | 48, 0.61 (0.15) |
| Other | 08, 0.82 (0.09) | 08, 0.56 (0.20) | 07, 0.63 (0.20) |
| <i>Mobility</i> | | | |
| Manual/power | 28, 0.73 (0.21) | 27, 0.48 (0.21) | 29, 0.59 (0.17) |
| Just manual | 20, 0.78 (0.10) | 19, 0.53 (0.18) | 20, 0.64 (0.13) |
| <i>Impairment</i> | | | |
| SCI | 36, 0.76 (0.17) | 36, 0.56 (0.19) | 37, 0.66 (0.13) |
| Other | 18, 0.74 (0.17) | 16, 0.43 (0.23) | 18, 0.53 (0.17) |
| <i>Funding</i> | | | |
| ACC | 22, 0.75 (0.21) | 22, 0.54 (0.18) | 22, 0.63 (0.13) |
| MoH | 18, 0.74 (0.17) | 18, 0.45 (0.23) | 18, 0.58 (0.16) |

Note: A higher global community access score indicated greater level of reported community access.

Reasons for community access changes

While the data analysis above indicates patterns regarding varying degrees of difference between difficulty accessing community items, and the three time periods, no causal inference can be drawn. To gain potential insight into the factors influencing participants change in accessing the community, participants were also asked that if their community access had changed between the six months prior to the first earthquake in September 2010 earthquake (time one), and during the last six months at time of survey completion (time three), what the influences on that change were. Participants could select as many options as necessary from a list (including 'other'), in no particular order. Fifty-six participants selected at least one option. The greatest number of participants (n=50, 78%) reported that the Canterbury earthquakes were an influence, with 17 (26.6%) reporting that a significant change in their health was an influence. Ten (15.6%) participants reported that a significant change in family and/or carer support was a major influence; 9 (14.1%) participants reported that housing relocation was a major influence; and 6 (9.4%) participants reported that a significant change to funding and/or finances was a major influence.

5.7.3 Reported social networks

Social networks and connections were felt to be an essential dimension of community, highlighted in theme three of Phase One of my research. Accordingly, in section five of the survey I examined participants' perspectives regarding social networks. Participants reported having a mostly positive sense of community (see Table 5.6). Forty two percent (n=25) of participants agreed (strongly agree or agree) that they felt a sense of community with others in their neighbourhood, compared with 17% (n=10) who did not feel a sense of community with others in their neighbourhood (strongly disagree or disagree). Forty one percent (n=24) of participants were neutral on the matter. Age, ethnicity, current mode of mobility, and funding were not significantly related to participants' current sense of community (see Table 5.6).

Despite a majority of participants reporting a positive sense of community, participants reported that their current sense of community had decreased (n=26, 40.6%) or was no different (n=31, 48.4%) compared with their sense of community during the six months prior to the first earthquake in September 2010 earthquake (time one). Similar results were observed when comparing participants' current sense of community with their sense of

community during the six months following the first earthquake in September 2010 (time two), with $n=31$ (48.8%) reporting it had decreased, and $n=28$ reporting it was no different ($n=28$, 43.8%). No participant reported an increased sense of community compared with either their sense of community during the six months prior to the first earthquake in September 2010 earthquake (time one), or during the six months following the first earthquake in September 2010 (time two). At time of survey completion, a majority of participants ($n=57$, 89.1%) reported they did have someone to turn to. Family ($n=54$, 84.4%), friends ($n=44$, 68.8%), and health or social support worker ($n=20$, 31.3%) were the most reported sources of support.

Table 5.6. Participants' rating of their current sense of community (time three) with others in their neighbourhood overall partitioned by sample characteristics (N=59).

| "I feel a sense of community with others in my neighbourhood" | | | | | |
|---|----------------------------|-------------------|------------------|----------------|-------------------------|
| | Strongly disagree n (%) | Disagree n (%) | Neither n (%) | Agree n (%) | Strongly agree n (%) |
| <i>Gender</i> | | | | | |
| Male | 2 (5.6) | 4 (11.1) | 16 (44.4) | 11 (30.6) | 3 (8.3) |
| Female | 1 (4.3) | 3 (13.0) | 8 (34.8) | 10 (43.5) | 1 (4.3) |
| <i>Age (years)</i> | | | | | |
| ≤50 | 3 (10.3) | 1 (3.4) | 10 (34.5) | 13 (44.8) | 2 (6.9) |
| >50 | 0 (0.0) | 6 (20.7) | 13 (44.8) | 8 (27.6) | 2 (6.9) |
| <i>Ethnicity</i> | | | | | |
| NZ European | 2 (3.9) | 7 (13.7) | 20 (39.2) | 18 (35.3) | 4 (7.8) |
| Other | 1 (12.5) | 0 (0.0) | 4 (50.0) | 3 (37.5) | 0 (0.0) |
| <i>Mobility</i> | | | | | |
| Manual/power | 3 (9.7) | 5 (16.1) | 12 (38.7) | 10 (32.3) | 1 (3.2) |
| Manual only | 0 (0.0) | 2 (9.1) | 10 (45.5) | 7 (31.8) | 3 (13.6) |
| <i>Impairment</i> | | | | | |
| SCI | 1 (2.6) | 4 (10.3) | 17 (43.6) | 15 (38.5) | 2 (5.1) |
| Other | 2 (10.0) | 3 (15.0) | 7 (35.0) | 6 (30.0) | 2 (10.0) |
| <i>Funding</i> | | | | | |
| ACC | 1 (4.2) | 3 (12.5) | 10 (41.7) | 10 (41.7) | 0 (0.0) |
| MoH | 2 (11.1) | 1 (5.6) | 8 (44.4) | 6 (33.3) | 1 (5.6) |

There were several associations in Table 5.3 between accessibility and social connectedness that deserve consideration here. For example, the domain of *accessing places for social interactions* had moderately positive correlations with several community access domains that were physical in nature including accessing foot paths due to uneven surfaces ($r = 0.57$), accessing foot paths due to repair ($r = 0.63$), car parks ($r = 0.52$), and entry and access within buildings ($r = 0.63$). In addition, accessing foot paths due to uneven surfaces, and accessing foot paths due to repair, had moderately positive correlations with entry and access within buildings ($r = 0.68$ and $r = 0.70$ respectively), and access to public places ($r = 0.58$ and $r = 0.60$ respectively). In addition, difficulty in accessing car parks was related to a difficulty with access in entry and access within buildings ($r = 0.48$), and access to public places ($r = 0.41$). These data can be interpreted as supporting the concept that community is a dynamic interaction involving people and places, and that difficulty in accessing places impedes the ability of participants to be connected to their social networks.

5.7.4 Perceived opportunity for accessibility

A further area of focus in the survey was to understand participants' perceptions regarding the opportunity to improve accessibility following the earthquakes. The concept of opportunity appeared frequently in the findings of Phase One, primarily in theme four *opportunity found* (see section 4.4.5), and theme five *opportunity lost* (see section 4.4.6). In the survey, question 37 asked participants to rate the likelihood of whether an opportunity to improve accessibility following the September 2010 earthquake exists. Twenty-eight (48%) participants reported that since the September 2010 earthquake, the level of opportunity to improve accessibility was non-existent, very low, or low. Thirty (52%) participants reported the level of opportunity to improve accessibility to be medium, high, or very high. Age, ethnicity, current mode of mobility, and funding were not significantly related to participants' perceived level of opportunity to improve accessibility (see Table 5.7).

Table 5.7. Participants' rating of perceived level of opportunity to improve accessibility in the time since the September 2010 earthquake between subgroups (N=58).

| "I feel that since September 2010, the opportunity to improve accessibility in my community is..." | | | | | | |
|--|-----------------------|-------------------|--------------|-----------------|---------------|--------------------|
| | Non-existent n (%) | Very low n (%) | Low n (%) | Medium n (%) | High n (%) | Very high n (%) |
| <i>Gender</i> | | | | | | |
| Male | 1 (2.9) | 8 (22.9) | 6 (17.1) | 11 (31.4) | 7 (20.0) | 2 (5.7) |
| Female | 1 (4.3) | 7 (30.4) | 5 (21.7) | 3 (13.0) | 3 (13.0) | 4 (17.4) |
| <i>Age (years)</i> | | | | | | |
| ≤50 | 2 (7.1) | 8 (28.6) | 4 (14.3) | 6 (21.4) | 5 (17.9) | 3 (10.7) |
| >50 | 0 (0.0) | 7 (24.1) | 7 (24.1) | 7 (24.1) | 5 (17.2) | 3 (10.3) |
| <i>Ethnicity</i> | | | | | | |
| NZ European | 1 (2.0) | 15 (29.4) | 10 (19.6) | 12 (23.5) | 7 (13.7) | 6 (11.8) |
| Other | 1 (14.3) | 0 (0.0) | 1 (14.3) | 2 (28.6) | 3 (42.9) | 0 (0.0) |
| <i>Mobility</i> | | | | | | |
| Manual/power | 2 (6.7) | 10 (33.3) | 7 (23.3) | 4 (13.3) | 4 (13.3) | 3 (10.0) |
| Manual only | 0 (0.0) | 4 (18.2) | 2 (9.1) | 8 (36.4) | 5 (22.7) | 3 (13.6) |
| <i>Impairment</i> | | | | | | |
| SCI | 0 (0.0) | 8 (21.1) | 10 (26.3) | 11 (28.9) | 6 (15.8) | 3 (7.9) |
| Other | 2 (10.0) | 7 (35.0) | 1 (5.0) | 3 (15.0) | 4 (20.0) | 3 (15.0) |
| <i>Funding</i> | | | | | | |
| ACC | 0 (0.0) | 7 (29.2) | 3 (12.5) | 9 (37.5) | 2 (8.3) | 3 (12.5) |
| MoH | 2 (11.1) | 4 (22.2) | 3 (16.7) | 1 (5.6) | 6 (33.3) | 2 (11.1) |

In Phase One the notion that the opportunity to increase accessibility was waning, and may have been lost, influenced question 38 of the survey, which asked participants to indicate whether or not they felt the opportunity to improve accessibility had *changed* since the September 2010 earthquake. Twenty-three (39.7%) participants reported that the opportunity to improve accessibility had not changed, followed by 20 (34.5%) who felt it had decreased, with 15 (25.9%) reporting that it had increased. In addition, participants in Phase One expressed concern that a reduced opportunity may be associated with the ability of decision-makers in the recovery of Christchurch city to prioritise accessibility. Reflecting this, survey participants were asked to rate the level of confidence in decisions surrounding the rebuild. Specifically, participants were asked to rate their level of confidence in three entities who all play a large role in the rebuild of Canterbury: central government; local council; and building developers (see Table 5.8). Participants were more likely to report ‘not at all confident’ or ‘not very confident’ compared with ‘confident’ or ‘very confident’ for all three entities: central government (n=39, 70.9% vs. n=8, 14.5%); Local council (n=28, 50.0% vs. n=10, 17.8%); and for building developers (n=31, 56.3% vs. n=6, 10.9%).

Table 5.8. Participant's current level perceived confidence in the decisions of key rebuild stakeholders to promote increased accessibility (N=64).

| | Not at all confident n (%) | Not very confident n (%) | Neutral n (%) | Confident n (%) | Very confident n (%) | Don't know n |
|------------------------|----------------------------------|--------------------------------|------------------|--------------------|-------------------------|-----------------|
| Central government | 39 (70.9) | 0 (0.0) | 8 (14.5) | 7 (12.7) | 1 (1.8) | 4 |
| Local council | 28 (50.0) | 0 (0.0) | 18 (32.1) | 9 (16.0) | 1 (1.8) | 3 |
| Building developers | 18 (32.7) | 13 (23.6) | 18 (32.7) | 6 (10.9) | 0 (0.0) | 3 |

5.7.5 Comparison with CERA Well Being Survey data

As outlined in the survey development section (see section 5.3), it was intended that the data from the survey used in Phase Two would be compared with the data from the September 2015 CERA Wellbeing Survey. Discussion about, and agreement to, provide individual-level data for people identifying as having a disability was undertaken prior to the commencement of this study (Matthew Males, Advisor Social and Cultural Outcomes at CERA, personal communication, December 21, 2015). However, CERA disbanded in April 2016 and the governance of the CERA Wellbeing Survey data was taken over by the Canterbury District Health Board (CDHB) ("Canterbury Wellbeing Survey," 2016). Despite a successful application indicating that the CERA Wellbeing Survey data would be made available to me, the CDHB were developing new protocols and restructuring the staff tasked with managing these survey data. At the time of writing, I had not been granted access to the data needed to make comparisons with my survey data. As a result, direct (statistical) comparison between my survey data and the CERA Wellbeing survey could not be included in my thesis, but will form part of ensuing publications upon its release.

Despite the lack of individual level data regarding people who identified as having a disability, some broad comparison with patterns in the CERA survey can be discussed. Eighteen per cent (n=218) of people in the September 2015 CWS in Christchurch city identified as having a disability (Canterbury Earthquake Recovery Authority, 2015c). People who identified as having a disability were more likely to report being impacted in a number of the same areas as reported in my survey. For example, people who identified as having a disability were among the subgroups that were more likely than average to rate the loss of meeting places for community meetings to have a moderate or major impact on their everyday lives (16% compared to 11%). People who identified as having a disability were also among the subgroups that were more likely than average to lack confidence in earthquake recovery decisions by local authorities (49% compared to 26%). This lack of confidence by people who identified as having a disability in decision-making also extended to individual agencies, such as CERA (49% compared to 29%) and local council (39% compared to 31%). Further, people who identified as having a disability were more likely than average to be dissatisfied with the opportunities available to influence earthquake recovery decisions over time (43% compared to 24%). While not statistically significant, the data above suggest a broad association between the sample in the CWS and the sample in my

survey in the areas of loss of meeting places, and confidence in decision makers, and opportunities to influence decision-makers.

5.8 Discussion

Some broad patterns present in the survey results are described below, followed by a discussion regarding the unsuccessful use of RDS in this study. A full integrative discussion and interpretation of Phase One and Two findings is conducted in Chapter Six.

5.8.1 Patterns in survey data

Participants identified the six months after the 2010 earthquake as the most challenging with regard to community access. Of the three six-month periods investigated within this survey, the mean global community access score was lowest for the six months following the first earthquake in September 2010 (time two), and the percentage of participants who identified substantial difficulty in accessing community areas was highest for this period. This finding aligns with a majority of literature exploring the impact of disasters on disabled populations, which suggests that disabled populations face increased challenges in the initial period following a natural disaster (Phibbs et al., 2012; Rooney & White, 2007; White, Fox, Rooney, & Cahill, 2007).

However, the survey findings extend the disability and disaster literature by indicating that community inclusion for wheelchair users is still challenging four years following the initial event. For example, the difficulty in accessing many community areas during the last six months at time of survey completion (time three) (e.g. finding accessible housing, car parks, public places, and footpaths) was still significantly higher than the six months prior to the first earthquake in September 2010 earthquake (time one). Also, the global community access score for the last six months at time of survey completion (time three) was still significantly lower than the six months prior to the first earthquake in September 2010 earthquake (time one), indicating that community access had not returned to pre-earthquake levels, let alone improved beyond pre-earthquake levels. These findings support the small amount of literature that has explored the longer-term impact of natural disasters for disabled populations (Stough et al., 2010; Stough et al., 2016).

A further pattern in the survey findings was participants' low level of confidence in decision-makers' ability to make accessible friendly decisions as Christchurch rebuilds. Participants in the present survey reported much lower levels of confidence than were reported in the CERA

well-being survey. For example, in the September 2015 CERA well-being survey, 40% of Christchurch residents (disabled and non-disabled) expressed low levels of confidence (not at all confident, or not very confident) that recovery-related decisions of local authorities were in the best interests of greater Christchurch (Canterbury Earthquake Recovery Authority, 2015a). This contrasts with 70.9% participants in my survey who had low confidence in central government to prioritise accessibility, 50.0% for local government, and 56.3% for developers. While results of the CERA survey are not particular to disability or accessibility, the finding of my survey that accessibility is perceived to be a low priority, can be set within the wider context where 40% of Christchurch residents have a low-level of confidence in the decision-making of local authorities.

The patterns outlined above, and how they contribute to the existing literature surrounding disaster and disability, is thoroughly explored in Chapter Six. The next section of this chapter I focus on the experience of using RDS as a sampling option, and potential reasons as to why it was unsuccessful, and what future research could learn from this experience.

5.8.2 Respondent driven sampling: a lack of traction

An abbreviated version of this section appears in the publication regarding the experience of using RDS (Bourke et al., 2016). Despite a rigorous recruitment process and offering incentivised participation, the use of RDS in this study failed as an effective sampling approach amongst wheelchair users in New Zealand. This experience differed substantially from other web-based RDS studies which report successful recruitment of sufficiently large participant numbers to reach equilibrium. However, other web-based RDS studies have not been without recruitment difficulties. For example, Stromdahl, Lu, Bengtsson, Liljeros, and Thorson (2016) conducted a web-based RDS study exploring the behaviour of men who have sex with men in Sweden, and while enrolling 123 participants, this was not sufficient to reach equilibrium and they were unable to calculate valid unbiased population estimates.

There are a number of possible explanations as to why RDS in the present study was unsuccessful. First, the target population of the study was novel compared with hidden populations generally targeted by RDS studies. Research using RDS typically samples stigmatised populations, that often have strong internal networks, such as those with greater risk of HIV, including injecting drug users (Young et al., 2014), men who have sex with men (Philips et al., 2014; Stromdahl et al., 2016), and sex workers (Simic, Johnson, et al., 2006). Wheelchair users have experienced increased integration into many societies in recent years

and are arguably less stigmatised, and possibly have weaker internal networks, when compared to populations traditionally sampled using RDS. Although the precise mechanism by which perceived stigma might affect RDS participation is unknown it, nonetheless, remains noteworthy.

Second, the use of an unguaranteed reward (entry into a draw for an iPad) for survey completion has not been previously reported in RDS studies. This lack of guaranteed reward may have influenced participation. In addition, RDS studies often offer participants additional non-monetary free services, for example those related to the mitigation of HIV risk, such as counselling, referral for clinical follow-up, and educational material (Malekinejad et al., 2008). Our study did not offer participants any free services.

Third, specific aspects of the RDS recruitment process could have influenced response rates. For example, to circulate the three recruitment codes, participants were asked to create an individual email for each peer, insert one recruitment code into each email, copy and paste the short message about the survey and link to the survey, and send it to the peer they wished to recruit. The time and effort this required could have deterred participants from taking part. An alternative option could have been to send participants who completed the survey a single email for each unique recruitment code, which included a pre-prepared message and link to the survey, and asked participants to forward each email on to their chosen peer with 'one click'. This was used successfully by both Stromdahl et al. (Stromdahl et al., 2016) and Wejnert and Heckathorn (Wejnert & Heckathorn, 2008) in their web-based RDS studies.

Until such time as these factors, and their implications for recruitment, are better understood, using RDS for recruiting wheelchairs users may have limited merit, and formative research is recommended to optimise success. Exploring the areas of network characteristics, acceptability of RDS, appropriate incentive options, and seed selection have all been suggested as important for assessing the feasibility and appropriateness of RDS in certain populations (Simic, Johnson, et al., 2006). Specifically, formative research regarding specific seed selection is warranted. Motivated seeds with large network contacts can improve recruitment effectiveness. Indeed, one RDS study exploring people who inject drugs in Sydney, Australia, reported that 80% of their participants resulted from one seed (Paquette, Bryant, Crawford, & de Wit, 2011).

5.8.3 Strengths and limitations

In this section I outline a number of limitations and strengths specific to Phase Two; discussion of the overall strengths and limitations of the thesis can be found in Chapter Six.

One limitation that requires acknowledgement is the ultimate reliance on a convenience sample. The relatively modest sample size recruited compromises the statistical power of some of the comparisons. As a result of being reliant on a convenience sampling, the sample is unlikely to be representative, and limits any generalisations of the findings to a wider population of wheelchair users. With no sampling frame, and the unsuccessful use of RDS, the ability to obtain a representative sample was difficult to impossible. Consequently, the results of the survey should not be extrapolated beyond the convenience sample. Despite having a convenience sample, several strengths deserve consideration, including a deliberate effort to obtain a representative sample, through the use of a novel sampling approach, RDS, in order to conduct as rigorous research as possible. Also, every effort was made to conduct a robust statistical analysis of the data. For example, when conducting analysis of the global community access scores, statistical methods were employed to account for the possibility of regression to the mean, a ubiquitous phenomenon which makes natural variation in repeated data look like a real change (Barnett et al., 2005). Finally, while the sample was ultimately a convenience sample, probability sample surveys can still provide illustrative accounts of the study population, and be used to generate hypotheses which can be later explored using probability sampling methods (Aday & Cornelius, 2006; Lavrakas, 2008).

Another limitation is the potential for recall bias. The survey was administered at a single point in time, four years after the September 2010 earthquake, and asked participants to recall the experience of a number of events in the six months prior to September 2010 and six months immediately after September 2010. Because the Canterbury earthquake sequence could in no way be anticipated, obtaining pre-earthquake data was not an available option, and as the study was only designed in the years following the earthquakes, asking participants to recall experience retrospectively was the only option. Consequently, the potential for recall bias must be acknowledged when interpreting the survey results.

A further limitation was the potential for respondent bias. Although the sample appeared to be quite diverse at face value regarding age, gender, type of wheelchair use, and time using a wheelchair, it is possible that those who responded to the survey were more or less likely to have a certain experience of community inclusion, which might not reflect how other

wheelchair users in Christchurch experience community inclusion. Furthermore, without knowing with certainty the total number of people who use wheelchairs in Christchurch, it is difficult to know the proportion of the population that was included in the sample.

An additional limitation was the questions used within the survey. For example, while the questions had face validity, they had not been standardised, and the psychometric properties of the questions and the survey are largely unknown. The scope of my research study did not promote extensive evaluation of the psychometric characteristics of the survey tool, for example test retest reliability and internal consistency, and such investigations would be warranted should the survey be used more extensively in the future. However, to minimise the impact of this limitation, the survey questions and format were pilot tested with three wheelchair users, and thesis supervisors. Feedback was then incorporated into the survey (see section 5.3.1). Also, a number of the questions were worded as per the CERA well-being survey, which had been developed with consultation and pretesting with a number of Christchurch residents.

Further limitations relate to aspects of the design of the study as it progressed. For example, the original intention to conduct a national survey and compare people living in Christchurch with people living outside of Christchurch, was revised following the poor recruitment rates during the RDS phase, to a regional sample. Likewise the original intention to conduct a comparison with the CERA well-being survey data also had to be revised due to administrative barriers accessing CERA well-being data through the disbandment of this Government body. These developments could not be foreseen, and data analyses were revised accordingly.

In sum, limitations identified in Phase Two of my research included an ultimate reliance on a convenience sample, the potential for recall bias, the small sample size, the potential for respondent bias, and an incomplete understanding of the psychometric properties of the survey. These limitations were mitigated by efforts to employ the novel sampling approach of RDS, employing robust statistical analysis, and conducting consultation and pilot testing during survey development. An overall summary of the strengths and limitations of the research design and findings of the entire thesis will be presented in Chapter Six.

5.8.4 Summary

In summary, this chapter has outlined the process involved in conducting Phase Two of my research, a cross-sectional survey of 64 wheelchair users. This discussion has briefly outlined two broad patterns in the survey findings. Community access was the most difficult during the six months following the first earthquake in September 2010 (time two), and while reducing somewhat during the last six months at time of survey completion (time three), was still challenging four years following the initial earthquake event and had not returned to access levels during the six months period prior to the first earthquake in September 2010 earthquake (time one). In addition, participants had low levels of confidence that stakeholders involved in the Christchurch rebuild will make decisions promoting accessibility. Finally, this chapter examined potential explanations as to why the use of RDS was unsuccessful. The novel research population and topic, the lack of guaranteed reward, no offer of free services, and the actual recruitment process used, may have separately and collectively influenced peoples' motivation to complete this survey. Despite the unsuccessful recruitment results using RDS, further research exploring the application of RDS in populations of wheelchair users would be warranted before discounting this sampling approach in this population. A thorough discussion examining the integration and implications of the combined datasets from Phase One and Phase Two is presented in the next chapter.

Chapter Six: Discussion

6.1 Introduction

The aim of this mixed methods study was to understand how people who use wheelchairs experienced community inclusion in the four years following the Christchurch earthquakes. This study was unique in that it examined the specific intersection between a population with certain functional needs (wheelchair users); a specific natural disaster (earthquakes); over a longer-term timeline (four years post-disaster). My research also used a novel method, RDS, with wheelchair users, which potentially enables unbiased population-based estimations.

This chapter presents three main areas. The first section examines the integrated findings from Phases One and Two, and importantly, how the findings of my research contribute to, and extend the disability and disaster literature. In this first section I also argue that the findings of my research reflect a concentrated example of how disability can manifest in non-disaster contexts. Disasters can increase the challenge for people living with disability through simply magnifying barriers that already exist in society regardless of a hazard (Alexander, 2015). Second, I explore how best these findings might contribute to positive social change thru mechanisms such as holistic dissemination approaches, co-production of recovery outcomes, and community oriented change. I also compare my findings in relation to the disability policy in New Zealand. Finally, I consider the methodological aim of my research: to address the inability to recruit representative samples of wheelchair users, or indeed, any other groups of people living with disability. I explore ways in which future disability research could better recruit participants, and potentially recruit representative samples.

The sum of the argument in Chapter Six is that the findings of my thesis contribute to the evidence base on which to inform sustainable, inclusive communities during the longer-term recovery phase following a disaster. Such evidence is necessary in order to address the gap in the literature which requires both more accounts of people who live with disability during the longer-term recovery post-disaster, and also the need for more information regarding disaster recovery for all of society more generally (Smith & Wenger, 2006). As Aldrich (2012) writes, “understanding what factors speed or impede disaster recovery is critical both for survivors and for decision makers who must allocate scarce resources after a crisis” (p. 4).

6.2 Interpreting integrated findings

My thesis employed a mixed methods design on the premise it would provide a more complete understanding of wheelchair users' experience of community inclusion than the utilization of one method only. As I discussed in Chapter Three (see section 3.5.3), the two phases of my research were integrated at two points: 1) when the data from Phase One informed the development of the survey administered in Phase Two, and 2) when both datasets were combined for an overall interpretation. This chapter addresses the latter, presenting an interpretation of the integrated findings from Phase One and Phase Two.

Interpreting the integrated findings occurred utilizing a triangulation protocol. The findings of Phase One and Phase Two were listed in a table, and then visually assessed in terms of convergence, divergence, and silence (see Table 6.1).

Table 6.1. List of findings of Phase One and Phase Two to interpret integrated findings.

| PHASE ONE | PHASE TWO |
|---|--|
| <p><i>Earthquakes magnified barriers</i></p> <ul style="list-style-type: none"> • Participants experienced numerous barriers to community inclusion • Many pre-existing barriers were magnified by the earthquakes • Magnified barriers reduced participants' degree of community inclusion and participation and created feelings of difference and frustration | <ul style="list-style-type: none"> • Participants reported that substantial difficulty was lowest for the six months pre-quake, which then rose sharply in the six months post-quake, and reduced slightly over the last six months, however still much higher than the pre-quake baseline. Significant difference for some items • Global community access score was highest the six months pre-quake, rose sharply post-quake, then dropped for last 6 months – indicating that community access had not returned to pre-earthquake levels, let alone improved beyond pre-earthquake levels. Significance reported between times. • Accessing places for social interactions had moderately positive correlations with several community access domains that were physical in nature including accessing foot paths due to uneven surfaces ($r = 0.57$), accessing foot paths due to repair ($r = 0.63$), car parks ($r = 0.52$), entry and access within buildings ($r = 0.63$), and access to public places ($r = 0.56$) <ul style="list-style-type: none"> ○ These data could be related to the findings that participants' sense of community had not increased since the earthquake, because difficulties with physical access areas such as foot paths and car parks hampered access to community spaces and opportunities to engage in social interactions. |
| <p><i>Community inclusion requires energy</i></p> <ul style="list-style-type: none"> • Participants articulated that at an individual level they were required to expend a great deal of energy to negotiate the barriers outlined in theme one • This energy was required prior to the earthquakes, and was increased by the consequences of the earthquake | <ul style="list-style-type: none"> • Fifty, 78.1%) reported that the Canterbury earthquakes were an influence in change to access • Seventeen (26.6%) reporting that a significant change in their health was an influence. |
| <p><i>Social connections are important</i></p> <ul style="list-style-type: none"> • Participants' social connections were a defining feature of community connection • Provided a sense of belonging, support, | <ul style="list-style-type: none"> • Ten (15.6%) participants reported that a significant change in family and/or carer support was a major influence; • Nine (14.1%) participants reported that housing relocation was a major influence • Six (9.4%) participants reported that a significant change to funding and/or finances was a major influence |

| | |
|---|---|
| <p>contributed to participants' wellbeing</p> <ul style="list-style-type: none"> Encouraged greater community inclusion and participation | <ul style="list-style-type: none"> Participants reported having a mostly positive sense of community (age, ethnicity, current mode of mobility, and funding were not significantly related to participants' current sense of community) |
| <p><i>An opportunity found?</i></p> <ul style="list-style-type: none"> A unique opportunity exists to build an accessible city The potential realization of this opportunity will play a key role in determining whether people who use wheelchairs feel included in their community | <ul style="list-style-type: none"> At the current time, a majority of participants (n=57, 89.1%) reported they did have someone to turn to <ul style="list-style-type: none"> Family (n=54, 84.4%), friends (n=44, 68.8%), and health or social support worker (n=20, 31.3%) were the most reported sources of support. Thirty (51.6%) reported the level of opportunity to improve accessibility to be medium, high, or very high. Twenty-eight (48.3%) participants reported the level of opportunity to improve accessibility to be non-existent, very low, or low |
| <p><i>An opportunity lost?</i></p> <ul style="list-style-type: none"> Participants were concerned that private developers were a potential barrier to the building of an accessible city Participants also emphasised that consultation with disabled people is vital Challenges regarding consultation included acknowledging the diverse needs within the wheelchair user population, not knowing who to contact to influence or create change, trying to unify disability lobby groups, and realising that democracy takes time | <ul style="list-style-type: none"> Age, ethnicity, current mode of mobility, and funding were not significantly related to participants' perceived level of opportunity to improve accessibility Twenty-three (39.7%) participants reported that the opportunity to improve accessibility had not changed, followed by 20 (34.5%) who felt it had decreased, with 15 (25.9%) reporting that it had increased. Participants were more likely to report 'not at all confident' or 'not very confident' compared with 'confident' or 'very confident' for all three entities: central government n=39, 70.9% vs. n=8, 14.5%); Local council (n=28, 50.0% vs. n=10, 17.8%); and for building developers (n=31, 56.3% vs. n=6, 10.9%) |

Comparing the findings from both phases in this way enabled the interpretation of higher order messages that are greater than the sum of the individual research components, a crucial requirement of mixed methods research (O'Cathain et al., 2010). The key messages of the integrated findings are:

1. Multiple, magnified and on-going barriers reduce community inclusion
2. Disabling barriers constitute social exclusion
3. A need to reconceptualise disability following disasters
4. Realising the opportunity for change
5. The need to co-produce socially transformative outcomes

The integrated findings are now examined within the literature, beginning with how the two phases contributed to participants' concept of community.

6.2.1 What is community inclusion for wheelchair users?

Participants felt that being part of a community was to interact with the people, in the places, that were important to them. Participants reported that community exclusion occurred when the accessibility of places was compromised (such as disrupted roading or evacuation from housing) and participants could not interact with people important to them.

The concepts of place and people have been identified in literature exploring wheelchair users' perspectives of community participation. For example, Hjelle and Vik (2011) conducted a focus group exploring perspectives of community participation with six wheelchair users in Norway. Participants highlighted the important role that place played in community participation. For participants in the Hjelle and Vik (2011) study, the freedom to choose was very important. Freedom to choose referred to having opportunities and choice regarding places they wished to go, such as shops, restaurants, footpaths, and doorways, when they wished. Physical barriers often limited participants' options.

The social component of participation has also been identified as a major theme for people who use wheelchairs. Hammel et al. (2008) conducted a multisite qualitative study which aimed to understand what participation meant to 63 participants with a variety of different impairments. Social connections ranged from intimate relationships to wider public and social interactions. Participants emphasised the importance of the reciprocal nature of social participation, for example having opportunities to provide support, and conversely, be

exposed to opportunities to receive support. Participants considered social participation as a right and also a responsibility, and that social connections, or lack thereof, could act as a facilitator, or indeed a barrier, to participation.

People and places, and the interaction between the two, provide a foundation for the term community inclusion throughout the analysis and interpretation of the combined datasets in this discussion chapter. That is, the term community inclusion refers to participants having the opportunity to be able to access the places in which the social interactions that are important to them can occur. For example section 6.2.3 examines how barriers reduced access to the physical environment, and section 6.2.4 highlights the importance of people, and that inaccessible places can compromise opportunities for social participation.

6.2.2 Multiple, magnified barriers

In this section I discuss how my findings support the stance that natural disasters can magnify pre-existing barriers to community inclusion, however extends the current knowledge base through providing data regarding a new population group/hazard combination, a new timeline over which the barriers were sustained, and how the barrier magnification progressed during that timeline.

My findings reflect the social vulnerability perspective, in which existing inequalities experienced by people living with disability can be magnified during a society's response to a natural disaster, making recovery even more challenging. (Hemingway & Priestley, 2006; Peek & Stough, 2010; Thomas et al., 2013). Importantly, the findings of my research compliment and build on this knowledge by indicating that magnified barriers can still be sustained four years after a disaster, and had not returned to pre-earthquake levels, let alone *improved beyond* pre-earthquake levels. Sustained magnified barriers for people who experience disability have been reported six months (Fox et al., 2010), and two years post-disaster (Stough et al., 2016), however have not been studied four years after a disaster. Also, the types of magnified barriers identified in my study (such as difficult accessing footpaths, car parks, public spaces, and accessing suitable housing) were also reported by people living with disability in the initial aftermath of the Canterbury earthquakes, providing further evidence that such barriers have indeed been sustained over the last four years, and have not been resolved (Brereton, 2012; Phibbs et al., 2012).

Furthermore, my research has extended the current literature through providing a nuanced consideration of how magnified barriers impacted on participants at three different time points during the four years post disaster. For example, Phase Two findings advanced Phase One findings through providing some precision regarding the timing over which these magnified barriers developed. Specifically, participants in Phase Two reported that out of the three time periods, community accessibility was the least difficult during the six months prior to the September 2010 earthquake. This difficulty then rose significantly in the six months following the September 2010 earthquake, and reduced slightly over the time period October 2015 – March 2016, however was still significantly higher than the pre-earthquake baseline. The global community access score (where a higher score reflected greater community access) provided further support for this pattern. The global community access score was highest during the six months prior to the September 2010 earthquake, was lowest during the six months following the September 2010 earthquake, before increasing for time period October 2015 – March 2016, yet still remained below the pre-earthquake baseline.

The fact that barriers were magnified suggests that there were pre-existing barriers *to* be magnified. Participants did report that many of the barriers magnified by the Canterbury earthquakes were indeed present, albeit in less severe ways, prior to the earthquakes. Participants in Phase One often commented on the barriers they faced when attempting to interact with friends or access places within the community before the earthquakes. For example, participants described the frustration of trying to access shops, encountering ramps that were too steep, and requiring help from shop assistants to enter stores. Participants in Phase Two reported that although the difficulty in accessing community areas was lowest for the prior to the September 2010 earthquake, access was still nonetheless, difficult. Likewise, while the global community access score was highest in the six months prior to the September 2010 earthquake, community access was still problematic.

The finding that barriers were present before the Canterbury earthquakes is consistent with the growing body of non-disaster research articulating how environmental barriers can limit access. Research suggests that the built, social, cultural, political, and economic environment(s) can limit (and by this logic potentially facilitate) community inclusion and social participation or people living with disability (Hammel et al., 2015; Hammel et al., 2008; Heinemann et al., 2015; Hjelle & Vik, 2011; Magasi et al., 2015; Whiteneck & Dijkers, 2009). Disabling barriers in the built environment can be attributed to the design and

construction of a built environment “infused with able-bodied values” (Imrie & Kumar, 1998, p. 358). Indeed, Bromley et al. (2007) examined wheelchair users’ perspectives of the accessibility of the city centre in Swansea, UK and reported a number of barriers attributed to a built environment created with an exclusive focus on the able-bodied population. Such exclusion reflects the idea of design apartheid (Imrie, 1996).

Participants in my research reported that the individual effort and energy needed to problem solve and deal with numerous environmental barriers actually became a barrier in its own right. Exerting this energy was required prior to the earthquakes, and was increased by the consequences of the earthquakes, resulting in fatigue from having to deal with overcoming such barriers. This is consistent with the dominant individualistic perspective of disability, where any interventions or solutions aimed at ameliorating restrictive environments are directed at the level of the individual. It is the individual who must negotiate such barriers through adapting themselves to suit the environment. As Bromley, Matthews, and Thomas (2007) argued, wheelchair users have to “exert their own agency to get by, and thus, survive by their own ingenuity and rarely through the predetermined volition of city planners, architects and city centre managers” (p. 240). This preoccupation negotiating barriers was time consuming and exhausting. A participant in the Hammel et al. (2015) study exclaimed “I spend all day troubleshooting the system, that's my job, even though, technically, I'm not employed” (p. 586). Consistent with this perspective, a case study by Fritz, Lysack, Luborsky, and Messinger (2015) reported how a person who used a power wheelchair due to a high-level SCI felt that the preparation required to problem solve when going to new places with new people was a roadblock to community participation.

A further consequence of a restrictive built environment highlighted by participants in my research was their concern regarding how and where to advocate for change. Opportunities to engage in community advocacy are important, as they provide a collective vehicle to promote change; to advocate individually is incredibly challenging and it is easy to become overwhelmed (Hammel et al., 2015). Knowing where, or who, to make contact with for instance, or even whether one possesses the capabilities needed to advocate for greater access, can thwart advocacy efforts (Hjelle & Vik, 2011; Imrie & Kumar, 1998). Furthermore, not all people living with disability are activists, and may feel pressured to join a disability organization in order to have an accessible community that is often required through legislation in the first place (Imrie & Kumar, 1998). For wheelchair users, and people

living with disability more generally, fighting for change, and indeed, even knowing where such a ‘battle’ takes place, becomes yet another external energy demand and creates yet another structural barrier.

A local example of having to advocate for inclusion can be illustrated through the opposition to section 133AX of New Zealand’s Building Amendment Bill. Following the Christchurch earthquakes, the Building Amendment Bill proposed section 133AX, which would allow local councils to grant a building consent for earthquake strengthening alterations, without requiring compliance to section 112(1) of the building code. Section 112(1) states that local councils must not grant consents for the alteration of buildings unless satisfied there will be provision for access, facilities, and escape from fire for people living with disabilities. A number of New Zealand disability organisations prepared a joint submission outlining their alarm about Section 133AX, arguing that when a group of people cannot access public buildings and participate in their community they become second-class citizens. Despite the submission, Section 133AX in the current 2016 Building Amendment Bill still has a clause which enables territorial authorities to grant consents without having the building complying to specified provisions in section 112.

This example illustrates how when policy which requires equality for people living with disability is jeopardised, people living with disability have to fight for what was rightfully theirs in the first instance, that is, access and facilities within public buildings in order to participate in the community. Furthermore, that a commitment to equity, as a principle or value, can be deemed surplus to requirement in certain situations.

In this section I have described how the findings of my research indicated how the Canterbury earthquakes magnified multiple, pre-existing barriers can be sustained and magnified four years after the initial disaster event. These barriers render genuine community inclusion as challenging, exhausting, and ultimately incomplete four years following the initial earthquake in 2010. The next section explores how many of these magnified barriers contributed to social exclusion, through restricting opportunities to engage with participants’ social connections.

6.2.3 Disabling barriers and social exclusion

In this section I discuss how my findings are consistent with arguments in the disability literature that assert physical barriers can limit opportunities for social engagement.

Importantly, my findings bring the issue of disabling barriers causing social exclusion into the longer-term disaster recovery context with people who use wheelchairs for the first time.

The role of social capital has been established as a critical resource in post-disaster recovery. Aldrich (2012) examined four major disasters throughout the twentieth century; the Tokyo earthquake in 1923, the Kobe earthquake in 1995, the Indian Ocean tsunami in 2004, and Hurricane Katrina in 2005, to understand how social resources influence post-disaster recovery. Aldrich (2012) argued that “high levels of social capital – more than such commonly referenced factors as socioeconomic conditions, population density, amount of damage or aid—serve as the core engine of recovery” (p. 15).

The magnified ongoing physical barriers following the Christchurch earthquakes inhibited opportunities to engage in social participation. For example, in Phase One, participants discussed how the failure to access places in the community, either through inaccessible car parks or buildings, contributed to feelings of discrimination, isolation, and an inability to take part. Phase Two findings complemented and extended this idea through demonstrating a positive correlation between difficulty accessing areas such as footpaths, car parks, and buildings – and difficulty accessing places for social interactions (see Table 5.3).

Participants in Phase One reported how social connections provided a sense of belonging and support, and interacting with people was a defining aspect of community inclusion.

Participants in Phase Two reported a mostly positive sense of community, and four years after the earthquakes, a majority of participants (n=57, 89%) reported they did have someone to turn to for support. Considering these data together I posit that when the physical barriers outlined above inhibit opportunities to engage with social connections, participants’ sense of belonging and support, and the experience of community inclusion and participation is diminished.

Instances of physical barriers reducing social participation have been highlighted in the non-disaster disability literature. A survey by Carpenter, Forwell, Jongbloed, and Backman (2007) exploring participation in 357 community-based adults with spinal-cord injury, identified that a lack of access to car parks, a lack of ramps, inaccessible washrooms and parks, and inaccessible transport options limited participants’ ability to participate in social activities. Imrie and Kumar (1998) reported similar findings where people living with disability felt

their social lives were negatively impacted by the restrictive physical construction of the built environment. Such restrictive environments can create feelings of invisibility and social anonymity, for example when the bar height is too high for bar staff to notice, and then serve, a wheelchair user. Fritz et al. (2015) reported that physical barriers in public places such as a lack of ramps, and moving inside restaurants and bars, inhibited opportunities to enjoy relationships and activities, creating not just a material barriers, but also “a less visible barrier to social participation: the loss of spontaneity” (Fritz et al., 2015, p. 1505).

Physical barriers can limit opportunities for social engagement; whether through material obstruction or indirectly through reducing spontaneity and energy due to the time and effort needed to plan activities. In such environments, people using wheelchairs, out of choice, or indeed necessity, may seek to avoid an environment, and experience social exclusion. When a group of people cannot access public buildings they become second-class citizens, who cannot work or participate in their community and thus become increasingly socially isolated. In the 2013 New Zealand Disability Survey (see section 2.2.3) disabled adults were more likely than non-disabled adults to report feelings of loneliness, and disabled adults were also less likely to participate in leisure activities compared with their non-disabled peers (Statistics New Zealand, 2014). Carpenter et al. (2007) reported that social support and engaging in social activities was associated with happiness and satisfaction, and that social isolation in turn made it difficult for participants in their study to engage in community participation.

The social connections identified by participants in my research mirrored many aspects reported in the literature. As reported above, physical barriers inhibiting opportunities for social engagement have previously been reported in non-disaster disability literature (Carpenter et al., 2007; Fritz et al., 2015). However, my research brings these concepts into the disaster literature, specifically regarding the intersection between wheelchair users during the longer-term recovery phase following an earthquake, for the first time. My thesis presents the argument that people and places are equally necessary to participants’ definition and experience of community. Disruption to one, in this case places, impedes the other, interacting with people. As such, the consequence of physical disruption is more than the creation of physical barriers: it strikes at the deeper meaning of community, that is, to interact with the people, in the places important to participants.

In the next section I juxtapose the post-earthquake opportunity to change the way wheelchair users can interact with people in the places which are important to them, with the growing anxiety that barriers to true community inclusion are still present four years on.

6.2.4 Reconceptualising disability in disaster contexts

In this section I argue that the findings of my research challenge the dominant social discourse that the vulnerability of people living with disability in disaster recovery contexts is ‘sited’ in the individual and their ‘impairment’. Hemingway and Priestley (2006) voiced concern that the term vulnerability, when assigned to people living with disability in disaster contexts, “is rarely theorised or explained” (p. 57). My research provides evidence that four years post-disaster, many of the barriers identified by a sample of wheelchair users were indeed a product of the wider environment. As such, I contend that it is the social and built environment that is ‘vulnerable’ and prone to disabling people, more so than a person’s functional impairment. The prominence of environmental barriers in participants’ accounts sets a foundation for the need to move to a socio-political analysis of disability in disaster recovery contexts. A socio-cultural analysis calls for refocusing the lens away from how an individual can best adapt their ‘limitations’ to an environment; to instead how societal, attitudinal, and physical environments inhibit community inclusion, and vice versa, how they can then enable and facilitate community inclusion (Hammel et al., 2015; Hammel et al., 2008; Whiteneck et al., 2004).

The findings of my thesis support the need for a social-cultural analysis to better understand how people living with disability experience disaster recovery contexts. Participants in Phase One highlighted how environmental factors (for example, the supply of accessible housing, inaccessible footpaths, and the availability of accessible car parks) can facilitate or hinder community inclusion. Other studies have found similar findings, where environmental factors such as inaccessible transport and housing, and the complex configuration of disaster recovery services have been the primary barriers to recovery, more so than the functional impairments of individuals (Stough et al., 2010; Stough et al., 2016). Moving towards a social-cultural analysis of disability in disaster contexts would also line with more recent conceptualisations of disability, such as the social model in the cultural (see section 2.2.1 and 4.5.1).

Outside disaster contexts, the idea that disability and participation arise from a dynamic interaction between built, social, cultural, political, and economic factors and a person's

individual circumstances is well established (Hammel et al., 2015; Hammel et al., 2008; Heinemann et al., 2015; Hjelle & Vik, 2011; Magasi et al., 2015; Whiteneck & Dijkers, 2009). While community participation demands both personal and societal responsibility (Hammel et al., 2008), individual self-determination can only occur in a community that provides opportunities to do so, and there is an overwhelming view that the crucial barriers to full participation result more from environmental barriers than individual impairments (Bromley et al., 2007; Imrie & Kumar, 1998).

A social-cultural analysis can also reframe the solutions needed to create an accessible community. Through ascertaining the degree to which environments do indeed facilitate access or not, a social cultural analysis can then help to identify the best strategies and solutions required to promote an accessible, inclusive community. For example, Bromley et al. (2007) argues that the ablest assumptions implicit within the social and built environment can be challenged through solutions such as a focus on creating urban environments based on universal design, where the diverse needs of the population are as best accommodated for as possible; and increased public awareness and social education highlighting the difficulties faced by people who use wheelchairs. A further key strategy identified by participants in my research, and strongly supported in the literature (Bromley et al., 2007; Imrie & Kumar, 1998) is the need for people living with disability to be involved as key partners in the development of policy and planning surrounding the creation of accessible community environments.

Moving from an individual vulnerability perspective to a social-cultural analysis that acknowledges the role that environmental barriers play in the community exclusion of people who use wheelchairs can help to redefine the contributing barriers to community inclusion, challenging the normalised expectation that people living with disability will incur losses following disasters due to their impairments (Fjord & Manderson, 2009). Building on this, a social-cultural analysis can also help to identify effective strategies to promote an accessible, inclusive community. In the next section I argue that my findings support the premise that an unprecedented opportunity exists to greatly improve the community inclusion experience for people who use wheelchairs.

6.2.5 Realising the opportunity for change

In this section I draw together the previous three sections by presenting how the integrated findings from Phases One and Two support the premise that an unprecedented opportunity

exists to greatly improve the community inclusion experience for people who use wheelchairs. Participants in Phase One emphasised that an unprecedented opportunity exists to create an accessible city and reduce barriers to community inclusion as Christchurch rebuilds and recovers. The scale of reconstruction following a disaster, like the 2010/2011 earthquakes in Christchurch, is of such a magnitude that the infrastructure is subject to change not normally attempted in non-disaster contexts.

Rebuilding and improving the built environment, including access into and around commercial premises and public buildings, public car parks and toilets, and more accessible public spaces, can be physically, politically, and commercially easier compared with changing the pre-earthquake environment. Priestley and Hemingway (2007) have suggested the breakdown of infrastructure following a disaster, and the recovery reconstruction, can offer unexpected opportunities to ‘improve the lives of disabled people, assert social rights more clearly, and to facilitate social and economic integration’ (p. 31). The concept of ‘building back better’ has been promoted in a variety of fields within disaster reconstruction and recovery literature (Mannakkara, 2014; World Health Organisation, 2013a), and the concept can indeed be applied to rebuilding a more inclusive community for people living with disability following a disaster.

However, if the recovery phase extends for a long period of time without any indication that opportunities are being acted upon, resultant uncertainty and anxiety can lead to people feeling less connected or part of the community (Blackman, Nakanishi, & Benson, 2016). Findings from Phase Two reflect concern and anxiety that the opportunity to improve accessibility is being, or will be, squandered as participants were *still* experiencing barriers to community inclusion four years after the initial September 2010 earthquake. For example, in Phase Two, only 52% of participants reported the level of opportunity to improve accessibility to be medium, high, or very high, and 23 (40%) participants reported that the opportunity to improve accessibility had not changed since the earthquakes.

Participants in Phase One voiced their concern that if this opportunity was not realised there was minimal hope of it happening in the future. Participants were concerned that if a visible demand for accessibility from the disability community diminished, decision makers, whether local authorities or developers, would not react. As Participant 4 suggested in Phase One, *‘this is the opportunity and if we don’t do it I give up cause if we can’t get it right now there’s no hope’*. In the study by Stough et al. (2016) discussed earlier, the authors reported

similar findings with participants only making negative predictions about their recovery, and feeling as though their situations were never going to change. Stough et al. (2016) further argued that a failure to address the barriers faced by people living with disability following a disaster, is a failure to address structural and systematic factors that create disability more generally. The full inclusion of social participation of people living with disability is then unrealised.

Anxiety as to whether change will occur could also be linked to participants' lack of confidence in decision makers' ability to take full advantage of recreating an accessible community. For example, participants in both phases were concerned that private developers, local government, and central government might not rate the building of an accessible city as a key priority. Participants in Phase Two were more likely to report 'not at all confident' or 'not very confident' compared with 'confident' or 'very confident' for all three entities. The findings of my thesis specifically highlighted the tension that can exist between whether developers promote accessibility as a personal preference or whether they do it just because legislation requires them to. A similar idea was proposed by a participant in Hammel et al.'s (2008) study, who, when discussing societal attitudes surrounding the terms 'reasonable' and 'accommodation', felt there was an attitude of "well if we have to, we will and if we don't have to, we won't" (p. 586).

Anxiety regarding the loss of opportunity could also stem from the centralised 'command and control' approach inherent in the central government response to the Christchurch earthquake. Central government had unprecedented power over the recovery journey through the establishment of the Christchurch Earthquake Recovery Act in 2011 (see 2.2.3), which gave control to one government body (CERA), overseen by one government minister, to control the decisions surrounding the rebuild and recovery of Christchurch. This was considered appropriate in the short-term, as a clear decision-making pathway with strong leadership was required given the scale of the destruction and disruption to the function of Christchurch. However, this highly centralised, top-down model approach of recovery governance has now attracted criticism due to its inability to engage in meaningful community consultation, and the lack of power that has been given back to the local community, including the local council, as the recovery transitions into the longer term (Carins, 2013; Orchard & Peryman, 2012). Failure of recovery authorities to engage and gain

traction with community actors can increase tensions between community members and result in a less effective longer-term recovery (Blackman et al., 2016).

In the next section I explore the implications of the findings of my research, specifically, examining how an effective recovery in which transformative social change might occur is best realised.

6.3 Transformative social change

In the second main section of Chapter Six I argue how the findings of my research might best contribute to real social change. Biddle and Schafft (2015) argue that mixed methods researchers need to be more proactive in specifying the values inherent in their work, and that there needs to be more engagement in the “conversation about the social ends that our research and the methods serve” (p. 331). My research drew on pragmatism and on the transformative paradigm (see section 3.4) to employ an action-orientated design that could promote practical outcomes that would help to enable the realisation of my explicit value commitment to the full community inclusion for people living with disability. To best engage in the conversation about the social ends that my research serves, in this section I present recommendations for how the findings of my thesis can be best used to promote tangible ways in which people who use wheelchairs, and ideally the wider disabled population, can experience greater community inclusion.

6.3.1 Raising awareness through dissemination

Ameliorating and challenging many of the environmental barriers highlighted in this chapter can be achieved through raising this awareness within the domains of decision-makers, policymakers, and the private building industry. Arguments for increasing the public awareness of the challenges that wheelchair users face, as well as the wider disability community, are common. For example a participant in the Hjelle and Vik (2011) study remarked, “able-bodied people must become aware of how discriminated people with disabilities are” (p. 2483). Bromley et al. (2007) concurs and argues that public awareness and changing social attitudes must be a key goal to promote greater access for wheelchair users. Bromley et al. (2007) recommended that social education, even at a school level, would encourage attitudes more accommodating of accessibility, which in turn would hopefully feed through to improving community environments.

Mertens (2007) argued that the dissemination of research findings can be a key way in which research results can encourage and enhance social justice. In the case of the research in my thesis, disseminating the findings to the public, decision-makers, policymakers, and the private building industry through using creative and accessible methods could be an effective way of raising awareness. The dissemination plan includes presenting the findings and implications of my research at 1) the New Zealand Disability Matters conference (Disability Matters, 2017) in November 2017 (pending the acceptance of abstract), and at a monthly EDLG meeting in Christchurch in late 2017. People living with disability, disability advocates, and decision-makers at a local and central government level will be attending both events. Additional efforts for disseminating the findings of my research include collaborating with organisations such as Barrier Free New Zealand (Barrier Free, 2017) and Be.Accessible (BeAccessible, 2017) who both advocates strongly for an accessible and inclusive society in New Zealand (see section 6.3.4). Collaboration will explore potentially effective ways to disseminate findings, and may include printed material, videos, social media campaigns, and art exhibitions such as a photo or video installation depicting the challenges that people who use wheelchairs face. From my personal experience of using a wheelchair, I have often been surprised by peoples' lack of awareness of some of the day-to-day challenges I, and other wheelchair users, often face when negotiating community environments. In this regard I am sure I am also unaware of the difficulties people with other impairments face. This lack of awareness underscores the need to disseminate the research findings in my thesis as a tool to promote social change.

6.3.2 The legislative context

My findings that participants experienced magnified barriers to community inclusion four years after the September 2010 earthquake provide an example of the lived experience of accessibility and human rights legislation contradicting each other. Such a contradiction indicates that the level of expectation set out by policy and legislation has yet to be realised, or even enacted. For example, that one section of society, wheelchair users, experience limited access to the built environment and reduced opportunities for social interactions runs contrary to initiatives such as the Human Rights Act, the NZDS, and the UNCRPD.

As discussed in section 3.3, I believe there can be a strong relationship between disability advocacy and disability research. Robust disability research motivated by the positive transformation of people experiencing disability and their lives can contribute to evidence-

based advocacy (Mmatli, 2009). My findings support a number of national level reports completed between 2013 and 2015 contending that many barriers to community inclusion for people living with disability in New Zealand are still present (see section 2.2.3) despite legislation promoting full inclusion.

The post-earthquake context, the scale of reconstruction and visibility in the public eye, provides a unique opportunity for the public awareness of accessibility to be increased. However, if people who use wheelchairs are still experiencing community exclusion and discrimination once the rebuild is complete, an opportunity to promote genuine inclusiveness will have been greatly squandered; bringing into question whether government policy initiatives to promote accessibility have any real legitimacy in a pragmatic, practical sense.

The recent emergence of well-informed initiatives advocating strongly for a universally accessible society are a positive development required to enable a growing proportion of the New Zealand population to experience equal opportunities to work and live in their communities. To achieve such an outcome, community members and people living with disability must be co-creators of this change. The next section explores this argument and how it could be realised in the Canterbury context.

6.3.3 Co-production of recovery outcomes

The recovery period is not just an opportunity to rebuild for people living with disability, but crucially, to rebuild *with* people living with disability (Phillips, 2015). It is imperative that pathways for disability organisations to engage with recovery authorities are available. Stough et al. (2016) argued that meaningful engagement and partnership between local disabled communities and disaster recovery organizations provide a better alternative to the ‘top down’ approach that has been a traditional habit of recovery organizations, and that a key outcome of increased partnership between local disabled communities and disaster recovery planners is increased empowerment which helps to transcend the biomedical and individualised approach to disability and disaster (Winser, 2002).

Co-producing outcomes with community ‘actors’ can enable the building of new and repaired forms of social capital during the longer-term recovery following disasters. Blackman et al. (2016) have argued convincingly in this area, suggesting that while the top down decision-making process may be appropriate as communities recover in the short term following a disaster, the challenges present during longer-term community recovery require different

approaches. In particular, moving from short-term to longer-term recovery requires a transition period, in which successful and sustained recovery is much more likely when community members are thoroughly involved in the coproduction of recovery policy and implementation. Benefits of this partnership and coproduction include feelings of value, empowerment, and a sense of investment and responsibility regarding decisions as communities recover. Furthermore, the involvement of community members as co-producers of recovery decisions can both repair, and indeed build new reserves of social capital (Blackman et al., 2016).

Chenoweth (2004) produced a critical examination regarding the implications of social capital for the inclusion of people living with disability in community life. Proactivity was identified as a key element of social capital, so that people living with disability are the creators, rather than the consumers, of resources; to possess social capital is to have community members who are actively engaged in decisions solving both current and potential community problems. The next section explores the growing efforts from the community organisations who promote an inclusive society.

6.3.4 Community oriented change

Also relevant to this discussion is the fact that there is a growing movement of initiatives in New Zealand advocating strongly for an accessible society that provides equal opportunities for all New Zealanders. Examples of these initiatives include Barrier Free New Zealand (Barrier Free, 2017) and Be.Accessible (BeAccessible, 2017). Such initiatives reflect many of the themes highlighted in this chapter. For example, Be.Accessible aims to help make New Zealand a truly accessible country for all. This goal will only be achieved by addressing three areas in concert: the physical and information environment; the social environment; and the interpersonal environment.

Indeed, research examining the meaning and implementation of ‘building back better’ during disaster recovery highlights that community involvement is essential to develop recovery initiatives which understand the realistic needs of community members (Kennedy, Ashmore, Babister, & Kelman, 2008; Mannakkara, 2014). A local example of a disability organisation being involved in the Canterbury recovery process was the establishment of the EDLG in December 2011 (discussed earlier in section 4.5.2). Created and led by people living with disability, the EDLG was established to advocate for the rights of people living with disability during the recovery following the Canterbury earthquakes. The EDLG advocates

for the rebuilt Christchurch to be an accessible and liveable community for all citizens to participate in and belong to. Due to the complex nature of the earthquake recovery process, the EDLG realised early on that identifying and promoting central outcomes was crucial to ensuring advocacy occurred in a coordinated and comprehensive manner. To this end, the EDLG have focused their energies on outcomes in the following three areas: 1) the legal and regulatory framework governing accessibility, 2) leadership and promotion of access as benefiting the whole community, and 3) promotion and information to the community and general public about the benefits and issues surrounding access.

The EDLG has achieved significant progress in these areas so far, as the following examples show. Beginning with the legal and regulatory framework, the EDLG has worked with the Central City Development Unit (CCDU) who oversee many of the key public building projects in central Christchurch, to ensure access audits are being carried out on all major anchor projects at the tender, design, and construction phases (Earthquake Disability Leadership Group, 2014). In the second area of leadership, the EDLG is considering ways to make public submissions on emerging policy initiatives associated with accessibility and the rebuild, easier for people living with disability. Examples include letting members know of submission opportunities and making a submission template available for people unfamiliar with the submission process. Other initiatives include investigating ways to gather data regarding the economic benefits of accessibility and developing methods of monitoring progress of accessibility during the recovery. In regard to the third area, awareness and education, a major focus of the EDLG has been to accrue information about accessibility in one place, ranging from definitions of accessibility, to information about submissions, to requirements of the building code, and links to relevant organisations. To achieve this, the EDLG has worked with the CDHB to provide this information on the CDHB's health policy webpage (Earthquake Disability Leadership Group, 2014). The EDLG example is a pragmatic manifestation of how a disability organisation led by people living with disability can become involved in a disaster recovery process.

The recovery of Christchurch is ongoing. It remains to be seen whether the structural barriers outlined in my research will be removed, or whether new barriers will be created, as the infrastructure of Christchurch is rebuilt. To avoid squandering this opportunity for change, it is of paramount importance for central and local government, and the private building

industry, to partner with local disabled communities, such as the EDLG, to ensure an accessible, inclusive community is realised.

A partnership-based culture is at some level emerging. CERA was suspended in April 2016, and the responsibilities of CERA were allocated to a variety of organizations, including the CDHB, the Christchurch City Council, and Regenerate Christchurch. Regenerate Christchurch is a new agency tasked with leading the recovery and rebuilding of Christchurch. Unlike the top down model of CERA, Regenerate Christchurch is a partnership between central government, local government, community and local iwi. This model of partnership appears encouraging if genuine partnerships between people living with disability and decision-makers are to be realised.

Critical to quality evidence-based research is that it is founded on solid, robust methodological foundations. Large-scale population studies of wheelchair users are generally lacking internationally, potentially due to limited methods for recruitment. The next section considers what can be learnt regarding effective recruitment methods for wheelchair users based on the methodological experience of the research conducted in my thesis.

6.4 Recruitment methodologies in disability

A third part of Chapter Six relates to the methodological aim of my research: to address the inability to recruit representative samples of wheelchair users, or indeed, any other groups of people living with disability. Although my experience of using RDS was unsuccessful (see section 5.8.1), I believe a discussion about the ways future disability research might recruit representative samples is warranted. In this section I examine two areas that hold promise regarding how to gather representative samples. First, the establishment of registers that can provide a sampling frame, and second, utilizing social media as a recruitment tool.

My thesis employed recruitment methods typical of similar studies with wheelchair users, including the circulation of invitations via disability organisations, personal contacts, public notices, and requesting participants share amongst the personal networks (Edwards and McCluskey, 2010; Nary et al. 2012). Becker et al. (2004) suggests, “researchers must recognise the implications of the recruitment strategies for the conclusions that can be drawn from their findings” (p. 473). From a statistical viewpoint, the greatest failing of the recruitment approaches used in the quantitative phase of this thesis was the non-probabilistic nature of recruitment and the un-measurable (and potentially large) responder biases. As a

result, generalising the findings of Phase Two to the wider population is not possible. As mentioned in section 2.4, new and novel sampling strategies that can potentially deliver probabilistically samples warrant exploration.

6.4.1 Registers

Conducting research which can enable population-based estimates requires that all who are eligible (or almost all) have a non-zero probability of being included within the sample. Such population research is usually contingent on having an available sampling frame. Such a frame does not exist for wheelchair users and is a real underlying problem, and why even basic questions like how many wheelchair users live in New Zealand or Christchurch remain unknown.

One option for providing a sampling frame would be the establishment of a registry. Such a registry could take many forms, for example whether it is impairment-specific, or attempts to include all people living with disability. The latter would face many challenges such as the inclusion criteria. Deciding on the parameters of who might be included in such a registry would be a complex decision. How would disability be defined, and would people who fit the definition want to join, or even identify as having a disability? Further challenges were reported by Nicholls (2015), who surveyed wheelchair users in New Zealand regarding their perspectives regarding emergency preparedness, including the establishment of a registry for emergency preparedness. Although 90% of participants supported the idea of a registry for people living with disability, many (76%) were concerned regarding the collection and security of personal information, specifically, unauthorised access or privacy breaches. Kailes (2011) argued that if not thoroughly prepared, disability registries can risk neglecting the diverse needs of people living with disability, and there can be an underestimation of the resources required.

For registries to work they require a clear explanation about what they can and cannot do, sound governance and management, and effective information technology to collect and keep data safely. Of fundamental importance is stakeholder inclusion in registry development. People living with disability and their organisations must be involved in registry development, and that other stakeholders such as researchers, policymakers, and clinicians, are consulted regarding data set inclusion criteria (Kailes, 2011; Smaill et al., 2016).

The need for a New Zealand SCI registry has been discussed for a number of years. Potential benefits include a greater understanding of the SCI population, and the ability to inform the planning and delivery of services. Smaill et al. (2016) aimed to identify and establish a national spinal-cord injury database for those individuals who had sustained an injury prior to 1 January 1990 in New Zealand. A systematic search with organisations and clinical records uncovered an unexpectedly large ‘hidden’ spinal-cord injury population: ‘hidden’ because of fragmented, uncoordinated, and inconsistently collected data held through a variety of organisations. Building on the work of Smaill et al. (2016) and the New Zealand government's Spinal Cord Injury Action Plan, a prospective observational cohort registry, the New Zealand Spinal Cord Injury Register (NZSCIR) was implemented on August 1, 2016. All people in New Zealand who sustain a SCI are now approached and offered the chance to join the registry, and as time passes the possibility of retrospective data being entered to the registry will be explored (T. Croot, 2017, personal communication).

The establishment of registries with people living with disability (whether impairment based or broader) offers one option to provide a reliable sampling frame. Developing registries are complex, expensive, and data must be securely managed. Deciding on the inclusion criteria of the registry population requires broad development with the relevant stakeholders. One example New Zealand is the impairment based NZSCIR. Having only been established for one year at the time of writing, time will tell whether the NZSCIR provides a reliable sampling frame for researchers.

6.4.2 Social media as a recruitment tool

Another promising recruitment source is using social media sites such as Facebook and Twitter to recruit research participants. As traditional methods of recruiting participants encounter more challenges, health researchers are beginning to look towards more creative and effective recruitment methods such as the use of social media.

Household access to the internet in New Zealand is rising. In the 2013 Census 76.8% of households had access to the internet, an increase from 60.5% in 2006 (Statistics New Zealand, 2013). Some estimates of Internet use in New Zealand are as high as 89.4% (Internet Live Stats, 2016). The Internet in New Zealand 2015 survey reported that visiting social network sites (such as Facebook, LinkedIn, YouTube, and Instagram) was the second most popular activity amongst Internet users. People visit social networking sites frequently.

Eighty-five percent of users reported visiting social networking sites monthly, and 66% of users reported visiting social network sites daily (Crothers, Smith, Urale, & Bell, 2015).

The increased use of social networking sites in New Zealand offers a potential vehicle through which to recruit for research, and warrants consideration as a potentially effective mechanism to recruit wheelchair users. Using social media as a recruitment platform has been reported to increase sample sizes, reduce recruitment time, and be cost-effective (Park and Calamaro, 2013; Fenner, 2012). Ryan (2013) argues that a mixed recruitment approach, where social media is used in conjunction with traditional recruitment approaches, can be the most effective utilisation of recruiting through social media. There are a number of areas within the social media literature that have specific relevance to my research.

First, social media has been reported as an effective method to recruit young people into health research (Park and Calamaro, 2013; Fenner, 2012). Indeed, the Internet in New Zealand 2015 survey reported that social media use is most popular in the age group 16 – 29 years, and declines with age. The mean age of participants in Phase One was 49.3 years and in Phase Two was 50.5 years. As a key recruitment method in my thesis was circulating invitations through disability organisations, this mean age may be reflective of those more likely to be members of disability organisations. With no sampling frame available to know otherwise, it is quite possible that the average age of wheelchair users in New Zealand is much lower. Younger wheelchair users may be less likely to be members of disability organisations, making this cohort potentially more difficult to reach using traditional recruitment methods. Younger wheelchair users may be more likely to use social media to engage with social networks, disabled or otherwise.

Second, a number of studies have argued that social media provides a valuable platform to access and recruit difficult to reach populations, and minority populations (Ryan, 2013; Topolovec et al. 2016; O'Connor, 2014). Topolovec et al. (2016) conducted a literature review focused on comparing social media recruitment approaches with traditional recruitment methods. Eight out of a total of 30 studies in their review reported their target population was difficult to reach. Six out of this eight reported that social media was the most effective recruitment method. A study by O'Connor (2014) used Twitter to recruit mothers aged 35 years or older to complete a survey on the experience of pregnancy and giving birth. O'Connor (2014) recruited 299 participants, and although there was no sampling frame to know what proportion of total population the sample represented, the study still found

Twitter to be an accessible, effective, and cost-effective recruitment tool that provided participants with a transparent and anonymous research method in which to engage in health research.

In summary, future research with wheelchair users may indeed benefit from utilising social media as a recruitment platform. The traditional recruitment approaches used in disability research such as disability organisations, public notices, and personal networks are effective to an extent. However, to maximise the opportunity of recruiting wheelchair users who may not be socially connected to disability organisations or others who use wheelchairs; social media presents as an exciting addition to the toolkit of recruitment approaches. Indeed, the Internet has been promoted as a great source of information, and a contributor to social participation and quality of life for people experiencing disability, although barriers to Internet use, such as financial limitations or a lack of information technology skills can further disable people (Siegert, Snell, Sullivan, Babbage, & Freeman, 2015). In addition, recruitment using social media could still face problems when trying to generalise to a target population if the sampling frame for the population is still unavailable or inadequate. For example, large sample sizes are not always productive as they can have potentially large sampling biases if certain subgroups of the population are over represented. As mentioned earlier (see section 2.4), without an adequate sampling frame, determining such sampling biases is difficult.

6.5 Strengths and limitations

In this section I outline some strengths and limitations in the mixed method research. Where applicable, the processes employed to mitigate these limitations are noted.

As discussed above, the findings of my study reflect the experience of one section of the disability community. My research examined the specific intersection of people with certain functional needs, wheelchair users; regarding their community inclusion experience following a particular natural disaster, an earthquake; regarding a particular timeline, four years post-disaster. Findings may not reflect the experience of other populations who experience disability and vulnerability, for example those with visual or hearing impairments, cognitive impairments, mental health and aging populations. The research is also situated in a specific timeframe and disaster context i.e. the 2010/2011 earthquakes in Christchurch, New Zealand. How these findings relate to subsequent disasters, disasters of other types (e.g. floods or fires), or disasters in different ethnic or socioeconomic contexts (e.g. developing

countries) needs consideration. As a result, the findings might not have a direct application to other disaster recovery contexts.

Regarding the potential extrapolation of results, the findings of my research can be assessed in terms of their transferability (Biddle & Schafft, 2015). Transferability requires that a reader can evaluate research and make inferences about whether findings may have applicability to new contexts. This occurs through readers assessing the setting, participants, and the processes through which the findings were reached. To this end I made every effort to provide information and a rich description regarding the research setting, study participants, the methods and data analysis processes involved throughout, and the findings of the entire research project. One aim of my research was to compare data from my research with the CWS in order to make comparisons with the larger sample of people experiencing the recovery phase in Christchurch following the earthquakes. Unfortunately, this did not eventuate and was a great disappointment; especially as survey questions in Phase Two were deliberately uplifted from the CWS so that direct comparisons could be made. If the CWS data does become available in the future, it would be very interesting to compare outcomes between a sample of wheelchair users and non-wheelchair users. Such information could help to identify if and whether specific resources needed to be invested for different sections of the community.

Qualitative and quantitative research have been viewed as being incompatible due to differing assumptions underpinning both. In order to produce rigorous mixed method research, using both approaches, I employed several measures to describe why the mixing of two different approaches was appropriate. Each component method was conducted with the utmost rigour, for example by adhering to international guidelines for conducting and reporting on the component methods from each phase of the research. In Chapter Three I outlined the rationale, foundations, and sequence of the research design. The quality measures used in each phase were described respectively in Chapter Four and Chapter Five. A criticism of mixed methods research is a lack of adequate guidelines regarding how best to integrate the qualitative and quantitative components of a study, and neglecting to describe how the different components of a mixed methods research project are integrated and interpreted (O'Cathain et al., 2010; Polit & Beck, 2010). To address this issue I described the structured procedure employed to integrate and interpret the findings (see sections 3.6.1, 5.3, and 6.2).

Participants who identified as Māori (New Zealand's indigenous ethnicity) were underrepresented. The Treaty of Waitangi was signed in 1840 between the British government and Māori chiefs to protect the rights of Māori. Article Three of the Treaty has particular relevance as it assures Māori the benefits of modern society, including health care. Further, the development of the Māori Health Strategy named “He Korowai Oranga”, advocates for Māori families to be supported to achieve their maximum health and wellbeing, and that Māori health and disability outcomes may be improved through developing strong safe Māori communities. A more detailed and nuanced interpretation of Māori perspectives could increase knowledge regarding potentially unique needs and issues that may be pertinent to Māori.

Chapter Seven – Conclusions and future directions

7.1 Summary

Considered as a whole, the findings of this mixed methods study suggest that participants considered the term community to represent a dynamic interaction between physical places and opportunities for social interaction. The physical and social elements of community were both necessary for participants to feel included, and four years following the initial September 2010 earthquake; participants reported that sustained barriers inhibited their full community inclusion. The findings of this study also provide insight into how those barriers developed over time, with participants experiencing the greatest degree of community exclusion in the six-month period immediately following the September 2010 earthquake, and while this exclusion reduced somewhat, barriers to community inclusion were still present four years post-earthquake in higher levels than pre-earthquake levels.

The continued presence of barriers to community inclusion was concerning as negotiating these barriers was, for participants, exhausting and contributed to feelings of difference and discrimination. Because the cultural, social and political environment played a pivotal role in determining the barriers identified by participants, the recovery phase is an unprecedented opportunity to re-conceptualise disability as a product of the wider environment. In doing so, changing the way society both responds to disability *and* disaster, enabling people living with disability to be co-creators of an accessible and inclusive city during disaster recovery: an inclusive city that has the potential to remain long after the disaster event.

Furthermore, although the methodological aim of my thesis was ultimately unsuccessful in producing unbiased population-based estimates in the absence of a sampling frame, it has still provided insight into potentially achieving such goals in future disability research. For example, one failed test of RDS in disabled research does not discount its potential success in the future, and the possibility of registries and social media offer intriguing recruitment strategies.

In summary, the findings of the research conducted in the thesis extends the disability and disaster literature by demonstrating that magnified barriers to community inclusion for wheelchair users were sustained at four years post earthquake: a hitherto unexplored and unique combination of participant group, disaster context, and timeline in one piece of research. Further, the findings of my research have provided evidence as to the degree of the

barrier magnification over the four-year period by comparing three time periods. Finally, the unsuccessful application of a novel sampling approach provides exploratory evidence regarding how disability research in epidemiology may progress

7.2 Future research

A range of future research options could build on the thesis. One interesting area to explore would be the experience of accessibility and community inclusion as the rebuild continues. For example, my research suggests a gradual improvement in community access from the six months post-earthquake, however, four years after the earthquakes, community inclusion had not returned to pre-quake levels. The question arises: how long might this take? Will it ever eventuate? I feel that these questions provide a legitimate reason to conduct research into accessibility in the months and years ahead to contribute to the evidence base surrounding disability in disaster recovery contexts. As Smith and Wenger (2006) contend, disaster recovery is one of the least understood phases of disaster research, and more research is required to investigate and understand this crucial and important phase regarding how societies rebuild and recover following a disaster.

Disability diversity

People who live with disability are a heterogeneous population. For example, wheelchair use can represent a universal symbol of disability, which fails to acknowledge the diverse lived experience of all people living with disability (Titchkosky, 2011; Fritsch, 2013).

Conceptualising disability as a wheelchair can contribute to ideas of who is ‘legitimately’ disabled and who is not; people can be disabled, but not disabled, or not disabled in the right way: “disability is produced as a physical impairment that requires a wheelchair, side-lining and erasing other forms of impairment and disability, and the various needs of a disabled person” (Fritsch 2013, p. 140). Thus, future research that explores the experience of people living with other impairments could provide insight into whether the barriers to community inclusion after disaster identified in my research are experienced by other sections of the disability community.

To understand the full diversity within society, future research could also explore the perspectives of non-disabled stakeholders involved in the accessibility of the Christchurch community, for example, developers, architects, local council, and local disability organizations. For instance, if non-disabled stakeholders are included to view wheelchair use

as a static and universal symbol of disability then they may also think that disability can be known, contained, and addressed through seemingly simple solutions such as building ramps or posting the International Symbol of Accessibility (ISA) (Fritsch, 2013). This can lead to accessibility that is conditional on a narrow conception of what disability is.

Furthermore, using symbols such as the ISA can lead to feelings of having “done our duty for the disabled” (Fritsch, 2013, p. 144). By engendering a static, simple, and universal concept of disability and accessibility, symbols such as the ISA can appear to solve the problem of disability without ever needing to confront the contradictions of accessibility and the lived complexity of people who experience disability. Therefore, exploring how various stakeholders prioritise and perceive accessibility issues could provide a more rounded understanding of what is needed to realise change. Such information could also help identify which areas of society require education and/or awareness surrounding the importance of community inclusion for people living with disability. This can help direct resources to the areas of most need.

Epidemiology and disability

A third direction for future research, is considering ways in which epidemiology and disability research may progress and develop novel and robust methods, which enable probabilistic sampling for instance, to offer an insight into the personal and environmental determinants of disability which can be generalised to the target population. Integrating epidemiology into disability research does not need to signify a regression to the medicalisation of disability, nor classifying disability as deviating from a predetermined norm. Lollar and Anderson (2011) argue that a key step in ameliorating this concern is to train future public health professionals to understand that people living with disability are not by definition ill or unhealthy; but that there are numerous cultural, environmental, social determinants of disability.

Indeed, public health must continue to evolve to consider how social and environmental factors can hinder, and indeed, promote the health and well-being of people living with disability. Devereux and Bullock (2011) address this challenge directly, arguing that there is currently little overlap between disability studies and graduate public health courses that cover the social and behavioural dimensions of health. Devereux and Bullock (2011) go on to argue that public health requires a paradigmatic shift which acknowledges, and teaches, that there are social and environmental determinants of disability, and that until this occurs,

“public health will continue to be less attentive to the larger environment that contributes to people becoming disabled” (Devereux & Bullock, 2011, p. 74)

Conducting robust epidemiological research which acknowledges the social construction of disability, and promotes innovative methods that enable probability sampling, can ultimately, contribute to improving the quality of life of people experiencing disability and help to create a more accessible and inclusive community. As discussed in Chapter Six, potential options may include registries, and utilising social media, and also employing sampling strategies such as RDS with the learnt recommendations from my experience (see section 6.4).

7.3 Final words

The findings of my research highlight how participants experienced multiple significant and sustained barriers to community inclusion four years following a series of earthquakes. The barriers identified by participants were a product of the wider social political environment; this is the basis for my argument that to promote the community inclusion of people living with disability, the focus must move from a focus on individual vulnerability, to a focus on the social creation of disability in disaster recovery contexts. Post-disaster contexts can create unprecedented opportunities for city and community infrastructure re-imagination and change. Of critical importance for inclusive recovery is having pathways for people living with disability to be co-creators of this change, and to enable people living with disability to assert their right to exercise choice and control regarding accessing the places they wish, with the people they wish, when they wish. The inclusion of traditionally marginalised voices in decision-making processes can help to ensure that as communities recover following a major disaster they offer equal opportunities to, and value the diversity within our society. The findings of my thesis have also highlighted how the longer-term recovery context following a disaster provides a concentrated example of the way disabling barriers manifest in society more generally. As such, the rebuilding of a post-disaster environment and community provides a critical opportunity to ameliorate many of these disabling barriers, and act on policy that advocates for the equality of people living with disability.

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Appendices

Appendix A – Phase Two Māori consultation letter.

Appendix B – Phase One consumer consultation letter.

Appendix C – Phase One ethics approval letter.

Appendix D – Phase One invitation sent to disability organisations.

Appendix E – Phase One public poster invitation.

Appendix F – Phase One cover letter for participant information pack.

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Appendix I – Phase One individual interview guide

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Appendix K – Phase One Transcriber’s confidentiality agreement form.

Appendix L – Phase Two ethics approval letter.

Appendix M – Phase Two survey.

Appendix N – Phase Two email request to disability organisations to circulate invitations.

Appendix O –Phase Two participant information sheet (RDS).

Appendix P – Phase Two participant recruitment email (RDS).

Appendix Q –Phase Two ethics amendment letter (convenience sampling).

Appendix R –Phase Two survey invitation (convenience sampling)

Appendix S – Respondent Driven Sampling Publication

Appendix T – Publication from Phase One

Appendix A Phase Two Māori consultation letter.

Ngāi Tahu Consultation and Engagement Group

September 2nd, 2015

Tēnā koe, John

Re: Rebuilding following the Canterbury earthquakes: Wheelchair users' experience of community inclusion

This letter is written on behalf of the Ngāi Tahu Consultation and Engagement Group. We have read and considered your proposal and were in agreement that this is worthwhile and interesting project with potential benefits for Māori. The group has made the following recommendations to strengthen your proposal. It will be important to address these recommendations before you begin to gather information. If you would like to talk further to a committee member with particular health expertise, you can contact Annabel Ahuriri-Driscoll (ph 364 2987).

- Give careful thought to how you might share the findings of this research so that they are accessible to the people who are interested in them, and affected by them.
- Think about how you can ensure a sample of the Māori population in your participant cohort that will be sufficient to give integrity to any ethnicity-specific findings.
- Consider contacting Te Putahitanga (ph 0800 187689) regarding community organisations in ChCh that provide support for Māori people with disabilities. This may be a way to identify some potential participants.

Thank you for engaging with the Māori consultation process. This will strengthen your research proposal, support the University's Strategy for Māori Development, and increase the likelihood of success with external funding applications. It will also increase the likelihood that the outcomes of your research will be of benefit to Māori communities. We wish you all the best with your current project and look forward to hearing about future research plans.

The Ngāi Tahu Consultation and Engagement Group would appreciate a summary of your findings on completion of the current project. Please feel free to contact me if you have any further questions.

Nāku noa, nā



Dr Tracy Rohan

Research Consultant Māori

Research and Innovation

Room 244, Level 2, Psychology Building

ext 45520

Email: tracy.rohan@canterbury.ac.nz

Office Hours: Wednesdays 12.30- 5.00 pm, Thursdays and Fridays 8.00am to 4.30 pm

Appendix B Phase One consumer consultation letter.



C/o - The Burwood Academy of
Independent Living,
Burwood Hospital,
Private Bag 4708
Christchurch,
New Zealand
Email: euconsult@burwood.org.nz
Phone: +64 3 383 8671

27 November 2013

Dear Mr Bourke,

Re proposal titled: Rebuilding following the Canterbury earthquakes: Are wheelchair users remembered?

The End User Consultation Committee met with our end-user reference group on November 13th 2013 to discuss your research proposal. The Committee appreciated your willingness to attend and discuss your research with the end-user reference group. Your topic was considered extremely valuable considering the impact the Canterbury earthquakes have had on the wheelchair users in the community in the medium to longer term. The following suggestions are not mandatory and do not replace any issues highlighted by other ethical or cultural consultations that this research has been subject to. The Committee asks that you read the following suggestions in good faith and with an open mind.

Comments & suggestions:

- Consideration given not only to individual factors but also social factors as well, how existing social networks and disruption or otherwise to these networks affected participants perceived and/or actual social support.
- How long have they been a wheelchair user, ie the stage of life of participant
- The individual's reaction along with societal reaction and how it could affect policy and influence the rebuild.
- Involve participants from phase 1 in phase 2, use of focus groups in development of phase 1, consideration given to including the policy-decision makers and all the different stakeholders in the development of both phases.

We wish you every success in your research and ask that you supply the Committee with a copy of the research findings upon completion.

Yours sincerely,

Hamish Ramsden
End User Consultation Committee

Appendix C Phase One ethics approval letter.



HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2014/57

28 July 2014

John Bourke
School of Health Sciences
UNIVERSITY OF CANTERBURY

Dear John

The Human Ethics Committee advises that your research proposal "Rebuilding following the Canterbury earthquakes: are wheelchair users remembered?" has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 22 July 2014.

Best wishes for your project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'L. MacDonald'.

Lindsey MacDonald
Chair
University of Canterbury Human Ethics Committee

Appendix D Phase One invitation sent to disability organisations.

Dear xxxxxx,

My name is John Bourke, a Ph.D. student at the University of Canterbury. Due in part to my own experience as a wheelchair user, I am conducting a study that seeks to understand the experience of community inclusion for people who use wheelchairs during the recovery of Christchurch following the 2010/11 earthquakes.

I hope to recruit participants with the help of organisations such as yours. This email seeks your permission for me to send you an invitation that you would be willing to circulate amongst any of your members who live in Christchurch and use a wheelchair as their main form of mobility.

Anyone who sees the invitation and is interested in participating will be able to contact me for an information pack containing specific details of the study in order for them to make an informed decision whether or not to participate.

Please let me know if you are happy for me to send you an invitation for circulation amongst your members. If you have any questions please do not hesitate to contact me.

Kind regards,

John Bourke

Ph.D. Candidate

School of Health Sciences

University of Canterbury

E: john.bourke@pg.canterbury.nz

T: (03) 364 2987 extension 4128

M: 021 xxx xxxx

The Canterbury Recovery

Do you use a wheelchair and live in Christchurch?



A University of Canterbury study aims to explore whether people who use wheelchairs feel included in the community recovery three years after the 2010/11 earthquakes.

The study seeks people to share their experience by participating in a face-to-face interview. To be eligible for this study you need to use a wheelchair as your main form of mobility, currently live in the greater Christchurch area, and be 16 years or older.

This research is being done by John Bourke (himself a wheelchair user) to complete a Ph.D. degree. If you are interested, and would like an information pack, please contact John by email or phone using the details below:

John.bourke@pg.canterbury.ac.nz

Appendix F Phase One cover letter for participant information pack.

xx February 2014

Dear ...

Thank you for your interest in this study. This study aims to interview people who use wheelchairs regarding their experience of community inclusion four years after the 2010/11 earthquakes.

Please find the following enclosed:

- An information sheet explaining the study
- A consent form
- A stamped addressed envelope to return the consent form if you decide to take part

Please take the time to read through the information sheet and consent form.

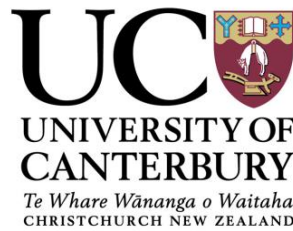
If you wish to take part in the study please sign the consent form and return it within the next seven days. Once I receive the signed consent form, I will contact you to arrange an interview.

Please do not hesitate to contact me (details below) if you wish to discuss any aspects of the study, or have any questions.

Kind regards,

John Bourke
PhD Candidate
School of Health Sciences
University of Canterbury
john.bourke@pg.canterbury.nz
(03) 364 2987 extension 4128
021 xxx xxx

Appendix G Phase One participant information sheet.



Rebuilding following the Canterbury earthquakes: Are wheelchair users remembered?

INFORMATION SHEET FOR PARTICIPANTS

This study aims to interview people who use wheelchairs regarding their experience of community inclusion three years after the 2010/11 earthquakes. This information sheet tells you who is conducting the study, the type of participants we aim to recruit, and what is involved if you do choose to take part. Please take the time to read through the information and feel free to contact one of the investigators for more information before making a decision (contact details are at the bottom of the last page).

Who is doing the study?

Hi there, my name is John Bourke and I am the principal investigator for this study. This study forms part of my Doctoral research at the University of Canterbury. I have been using a power wheelchair as my main form of mobility after having a spinal cord injury in 2005. My supervisors for this project are Professor Philip Schluter, Associate Professor Jean Hay-Smith and Dr Deborah Snell.

Aim of the study

For this study I aim to interview people who use wheelchairs regarding their experience of community inclusion three years after the 2010/11 earthquakes. I wish to explore the possible individual and social factors people feel are associated with inclusion in the community.

What types of participants are required?

I am interested in talking to people who use a wheelchair as their main form of mobility, are currently living in the greater Christchurch area, are 16 years or older, and are able to communicate their ideas to the researcher.

What will you be asked to do?

I will conduct individual interviews with participants. If you agree to take part in this study, I will contact you by phone to arrange a time for a face-to-face interview. You can choose a location that is convenient and accessible for you. This interview will be around 45 to 60 minutes long. At the end of the interview you are welcome to discuss any issues about your experience you feel are important, that were not covered by the questions I asked. A

summary of the interview will be sent back to you to check whether your thoughts and opinions have been accurately interpreted.

You (and other participants who are interviewed) will also be invited to join a focus group discussion once all the interviews are completed. The aim of the focus group is to discuss aspects of everyone's experience of using a wheelchair in the Christchurch recovery, in a group setting. You are free to opt in or out of this focus group discussion.

Benefits of the study

Although there are no other direct benefits from taking part, you might like to talk about your experience. I also hope that the results of this study will highlight factors important to people who use wheelchairs as greater Christchurch continues to recover. You will be offered a \$50 grocery or fuel voucher as koha from the University of Canterbury Ph.D. student research fund allocation.

What will happen to the information collected?

Your interview will be digitally recorded and transcribed. Recordings and transcriptions will only be seen and accessed by the study investigators. In the thesis (and any outputs to result from the study) you will be given a pseudonym so that your identity remains confidential. The data will be kept in a locked cabinet for 10 years before being destroyed. This is standard practice for research.

You can also choose to have your data included in the Quake Studies archive, an initiative developed by the University of Canterbury that aims to preserve the experiences and memories of people of the Canterbury region. This is optional and you can choose what data to include, who can see the data, and whether or not you want your name associated with the data. I can answer any questions you may have about data security surrounding the Quake Studies archive. For more information see <http://www.ceismic.org.nz>

Risks of the study

I understand that I am asking you to talk about a significant time in your life, and there is a chance this might be upsetting. You can stop the interview at any time without having to give a reason why, and you can also have a friend or family member present. If you become upset with any aspect of this study, or the subject of the earthquakes causes any distress, the following organisations can provide advocacy and assistance:

Health and Disability Services Consumer Advocate

The Health and Disability Advocacy can assist you with making sure your rights are respected. An advocate can listen to your concerns, provide information on your rights, and provide practical support regarding your options. You can contact a Christchurch-based advocate on (03) 377 7501

The Canterbury Earthquake Support Line

Canterbury Earthquake Support is a free and confidential service designed to support people following the Canterbury earthquakes. A coordinator can provide you with information and

connect you with a wide range of services that offer practical information, support, and advice. You can contact the Canterbury earthquake Support Line on 0800 777 846

The University of Canterbury Human Ethics Committee

The University of Canterbury Human Ethics Committee can help with any ethical concerns regarding the conduct of the study. Please address any concerns to Lindsey MacDonald, the Chair of the University of Canterbury's Human Ethics Committee via human-ethics@canterbury.ac.nz

Where can I get more information about the study?

John Bourke
PhD Candidate
School of Health Sciences
University of Canterbury
john.bourke@pg.canterbury.nz
(03) 364 2987 extension 4128

Professor Philip Schluter
Head of the School of Health Sciences
University of Canterbury
Philip.schluter@canterbury.ac.nz
(03) 364 2987 extension 44357

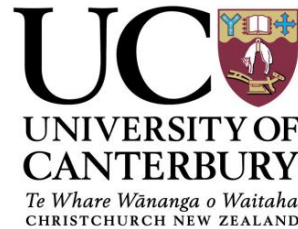
Associate Professor Jean Hay-Smith
Research Teaching and Research Unit,
University of Otago
jean.hay-smith@otago.ac.nz
(03) 474 7007 extension 8568

Dr Deborah Snell
Academic Director
Burwood Academy of Independent Living (BAIL)
Private Bag 4708
Christchurch 8140
debbie.snell@burwood.org.nz
(03) 383 6871

If you do choose to take part, please sign the consent form and return this in the pre-paid envelope provided. I will then contact you to arrange an interview.

This study has received ethical approval from the University of Canterbury's Human Ethics Committee, reference: HEC 2014/57.

Appendix H Phase One participant consent form.



Consent Form For Participants

Study: Rebuilding following the Canterbury earthquakes: Are wheelchair users remembered?

I have read the information sheet regarding the above study. I have had the opportunity to discuss any concerns with the study investigators. I am happy with the answers I have been given. I also understand that I am free to ask more questions if I need to. I have also had the opportunity to use whanau support or a friend to help me ask questions and to understand the study.

I understand that I will be asked to discuss aspects of my experience since the 2010/2011 Canterbury earthquakes during an interview, and will be invited to partake in a focus group at a later date. This consent form only applies to the interview and a separate consent will be asked for the focus group if you choose to participate in that.

I also understand that:

- My decision to take part in the study is entirely voluntary.
- I am free to withdraw from the study at any point without having to give a reason why.
- I can have a support person at my interview, and to help me with any questions I have about the study.
- I can stop the interview at any point without having to give a reason why.
- If I become upset I can discuss why with the interviewer if I wish to do so.
- I will be offered a list of people with whom I can discuss any issues that come up in the interview.
- My audiotape and interview transcript will be kept secure and in a locked cabinet or password protected file for 10 years.
- The results of the study will be published in John Bourke's PhD thesis. My identity will remain confidential in this thesis, and any future outputs, by using a pseudonym.
- I can contact John Bourke at any point during the study between the hours of 9am – 5pm on 364 2987 extension 4128.

I agree to take part in this study

(Signature)

(Witness Signature)

(Name)

(Witness Name)

Appendix I Phase One individual interview guide.

Questions.

1. When I say the word 'community' what does that word mean for you?
2. As a wheelchair user, what do you feel about your level of inclusion in the community during the recovery phase after the earthquakes?
3. As a wheelchair user, are there things that have supported your inclusion in the community during the recovery phase after the earthquakes?
4. As a wheelchair user, are there things that have acted as barriers to your inclusion in the community during the recovery phase after the earthquakes?
5. Has your experience of community inclusion changed since immediately after the earthquakes?
6. As a wheelchair user, do you feel there are any environmental factors that can act as a support or barrier to your inclusion in the community?
7. Do you feel that more could be done to ensure wheelchair users are included in the recovery?
8. As the recovery and rebuild continues, how do you feel about the creation of an accessible city?
9. Are there any other things you would like to discuss regarding your community inclusion as a wheelchair user following the earthquakes?

Possible prompts for all questions:

- a. Could you tell me a little more about that please?*
 - b. Could you think of an example?*
 - c. Who was involved?*
 - d. Why did that work so well?*
 - e. How could have that been improved?*
 - f. How did this make you feel?*
 - g. How does this make you feel now?*
 - h. Why do you think this is?*
 - i. How do you feel about that this long after the earthquake?*
-

Appendix J Phase One group interview guide

Candidate themes.

1. Inclusion takes energy

That community inclusion requires energy and that this determines participants' degree of community participation.

2. Social connections important

That having strong social connections encourages greater community inclusion and participation.

3. Earthquake magnifies barriers

That numerous barriers, many magnified by the earthquake, can reduce participants' degree of community inclusion and participation and create feelings of difference and frustration.

4. An opportunity for change

That a unique opportunity exists to build an accessible city, and that this will play a key role in determining whether people who use wheelchairs feel included in their community.

5. Is accessibility a public right or a private choice?

That central and local government and private industry will also play a key role in determining participants' level of community inclusion and participation.

Possible prompts for all candidate themes:

- a. How do you feel this theme captures your experience? Why?*
 - b. Could you tell me a little more about that please?*
 - c. Could you think of an example?*
 - d. Who was involved?*
 - e. How did this make you feel?*
 - f. How does this make you feel now?*
 - g. Why do you think this is?*
-

Appendix K Phase One Transcriber's confidentiality agreement form.



Rebuilding following the Canterbury earthquakes: Are wheelchair users remembered?

TRANSCRIBER'S CONFIDENTIALITY AGREEMENT

I Angela Marie Pope (full name printed) agree to transcribe the audio recordings provided to me.

I agree to keep confidential all of the information provided to me.

I will not make copies of the transcripts or keep a record of them.

Signature: Angela Pope Date: 16/11/14

Appendix L Phase Two ethics approval letter.



HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2015/117

23 September 2015

John Bourke
School of Health Sciences
UNIVERSITY OF CANTERBURY

Dear John

The Human Ethics Committee advises that your research proposal "Rebuilding following the Canterbury earthquakes: wheelchair users' experience of community inclusion (Phase two)" has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 23 September 2015.

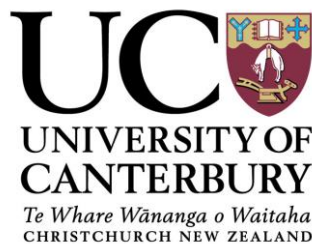
Best wishes for your project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'L. MacDonald'.

Lindsey MacDonald
Chair
University of Canterbury Human Ethics Committee

Appendix M Phase Two survey.



Wheelchair users' experience of community inclusion following the Canterbury earthquakes

Introduction

Thank you for agreeing to take part in this survey to find out about how wheelchair users have experienced community inclusion in the five years following the September 2010 Canterbury earthquake. This information can help local authorities understand the important factors for wheelchair users as communities rebuild.

Although this survey is framed around the Christchurch earthquakes, we are interested in hearing from people who live in all parts of New Zealand. This will help us to understand any differences in the experience of community inclusion between wheelchair users who live in Christchurch, and those who live in communities outside of Christchurch. The survey should take around 20-30 minutes to complete. When you complete the survey you will automatically enter the draw to win an iPad!!! (funded by the University of Canterbury PhD student research fund allocation. Prize drawn in 2016).

Once you finish, please pass the survey link to other wheelchair users you know that might be interested in completing the survey.

Your participation is completely voluntary. If you require any assistance to complete the survey please ask someone you trust to help you. If you have any questions about the survey please contact John Bourke on 021 xxx xxxx, or email john.bourke@pg.canterbury.ac.nz

If you have any concerns please contact the University of Canterbury's Human Ethics Committee, via human-ethics@canterbury.ac.nz or phone 364 2987 ext: 45588

Section 1: Background Information

Background information helps us to find out how much the survey sample is like the general population of New Zealand.

1. Please enter your email address (to contact you if you win the ipad competition):

2. On what date were you born? (enter dd/mm/yyyy e.g. 04/06/1989)

3. What is your gender? (select one)

- ☐ Male
- ☐ Female
- ☐ Gender Diverse

4. Which ethnic group do you belong to? (select all that apply)

- ☐ NZ European/Pakeha
- ☐ NZ Maori
- ☐ Pacific
- ☐ Asian
- ☐ Indian
- ☐ Prefer not to say
- ☐ Other (please specify)

5. Which best describes your household's annual income before tax?

- ☐ Loss
- ☐ No income
- ☐ Less than \$30,000
- ☐ \$60,001-\$100,000
- ☐ More than \$100,000
- ☐ Don't know
- ☐ Prefer not to say

6. Which of the following best describes your current usual housing situation:

- ☐ Home owner

- ☐ Renting
- ☐ Rehabilitation unit
- ☐ Long-term care facility
- ☐ Temporary accommodation
- ☐ Other (please specify)

7. Which of the following best describes your usual housing situation at the time of the September 2010 earthquake:

- ☐ Home owner
- ☐ Renting
- ☐ Rehabilitation unit
- ☐ Long-term care facility
- ☐ Temporary accommodation
- ☐ Other (please specify)

8. Which best describes your current usual living arrangement:

- ☐ Alone
- ☐ With spouse/partner, no children
- ☐ With spouse/partner and your children) or step-child (ren)
- ☐ With child (ren) or step-child (ren), but no other adult(s)
- ☐ With other family relatives
- ☐ With non-relatives
- ☐ Other (please specify)

9. Which best describes your usual living arrangement at the time of the September 2010 earthquake

- ☐ Alone
- ☐ With spouse/partner, no children
- ☐ With spouse/partner and your child (ren) or step-child (ren)
- ☐ With child (ren) or step-child (ren), but no other adult(s)
- ☐ With other family relatives
- ☐ With non-relatives
- ☐ Other (please specify)

10. Which area do you currently usually live in?

- ☐ Christchurch (red-zone)
- ☐ Christchurch (elsewhere)
- ☐ Other region in New Zealand (please specify)

11. Which area did you usually live in at the time of the September 2010 earthquake?

- ☐ Christchurch (red-zone)
- ☐ Christchurch (elsewhere)
- ☐ Other region in New Zealand (please specify)

12. What impact did the 2010/2011 Christchurch earthquakes have on your usual housing situation?

- ☐ None
- ☐ A small amount (e.g. minor house damage)
- ☐ A moderate amount (e.g. had to move temporarily)
- ☐ A significant amount (e.g. permanent relocation)
- ☐ Other (please specify)

Section 2: Mobility Information

Answers to these questions will help us understand your wheelchair use.

13. What is your current usual primary mode of mobility?

- ☐ A manual wheelchair
- ☐ A power wheelchair
- ☐ A mix of manual and power wheelchairs
- ☐ Other (please specify)

14. What was your usual primary mode of mobility at the time of the September 2010 earthquake?

- ☐ A manual wheelchair
- ☐ A power wheelchair
- ☐ A mix of manual and power wheelchairs
- ☐ Other (please specify)

15. In what year did you begin using a wheelchair as your usual primary mode of mobility? (e.g. 1996):

16. Which best describes the impairment that requires you to use a wheelchair? (select one)

- ☐ Spinal Cord Injury
- ☐ Cerebral Palsy
- ☐ Multiple Sclerosis
- ☐ Muscular Dystrophy
- ☐ Stroke
- ☐ Amputation
- ☐ Traumatic Brain Injury
- ☐ Other (please specify)

17. Do you receive home help and/or attendant care support? (e.g. for personal cares, driving, or housework)

- ☐ Yes
- ☐ No

18. If you answered Yes to Q19, approximately how many hours per day:

- ☐ 0-4
- ☐ 5-9
- ☐ 10-14
- ☐ 15-19
- ☐ 20-24

19. Do you receive financial support because of your impairment? (e.g. for care, equipment etc.)

- ☐ Yes
- ☐ No

20. If you answered Yes to Q21, who is the primary provider of that funding? (select one):

- ACC
- Ministry of Health
- Other (please specify)

Section 3: Earthquake Experience

This section asks about your earthquake exposure and experience.

21. Were you present in the Christchurch district during any of the following earthquakes? (select all that apply):

- ☐ September 4th 2010
- ☐ February 22nd 2011
- ☐ June 13th 2011
- ☐ December 22nd 2011

22. About how much time have you spent living in Christchurch in the 5 years since September in 2010?

- None or nearly none
- Some (long periods of time away — equal to or more than 2 years away)
- Most of the time (short periods of time away — less than 2 years away)
- The whole time or almost the whole time

23. Is Christchurch your primary place of residence?

- Yes
- No

24. If you answered Yes to Q25, was Christchurch your primary place of residence before September 2010?

- Yes
- No

25. If you answered No to Q26, in which month/year did Christchurch become your primary place of residence? (enter mm/yyyy e.g. 07/2011)

26. Would you say that your overall quality of life is (select one):

30. In the 6 months immediately before the time of the September 2010 earthquake how hard was it for you to:

| | Impossible | Always hard | Often hard | Occasionally hard | Never hard | Not applicable |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Access footpaths due to uneven surfaces | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Access footpaths due to repair and construction work | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Find suitable accessible housing | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Find accessible places for social interactions | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Access your workplace | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Access your education centre | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Receive attendant care services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Find accessible car parks | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Gain entry to, and move inside buildings built before the earthquakes | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Gain entry to, and move inside buildings built after the earthquakes | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Access public spaces in your community | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

31. If access has changed in the last 6 months, compared to the 6 months before the time of the September 2010 earthquake, is this because of (select all that apply):

- ☐ The Canterbury earthquakes
- ☐ A significant change in your health status
- ☐ Housing relocation
- ☐ Employment relocation
- ☐ A significant change in family/carer support
- ☐ A significant change to funding or finances
- ☐ Other (please specify)

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Section 5: Social Networks

This section asks about your social networks over the last four years. The term ‘sense of community’ refers to how included you feel with the people and in the places in your neighbourhood.

32. Thinking about the last 6 months, to what extent do you agree with the following statement?
“I feel a sense of community with others in my neighbourhood”
- ☐ Strongly disagree
 - ☐ Disagree
 - ☐ Neither disagree or agree
 - ☐ Agree
 - ☐ Strongly agree
33. How does this current sense of community with others in your neighbourhood in the last 6 months compare with what it was like in the 6 months after the time of the September 2010 earthquake?
- ☐ A decreased sense of community with others
 - ☐ No different
 - ☐ An increased sense of community with others
34. How does this current sense of community with others in your neighbourhood in the last 6 months compare with what it was like in the 6 months before the time of the September 2010 earthquake?
- ☐ A decreased sense of community with others
 - ☐ No different
 - ☐ An increased sense of community with others
35. If you were faced with another serious illness or injury, or needed emotional support during a difficult time, is there someone you could turn to for help?
- ☐ Yes
 - ☐ No
 - ☐ Not sure
36. If you answered Yes to Q37, who would you turn to for help? (select all that apply)
- ☐ Family

- ☐ Friends
- ☐ Faith-based group
- ☐ Cultural group
- ☐ Neighbourhood group
- ☐ Clubs and societies
- ☐ Health or social support worker
- ☐ Parenting networks
- ☐ Work colleagues
- ☐ Online community
- ☐ Rūnanga
- ☐ Other (please specify)

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Section 6: The Future

This section asks your opinion about accessibility in your community in the future. The term ‘accessibility’ refers to the ability for you to take part in your community e.g. having the ability to access places and interact with the people that are important to you.

37. Select the option that you think best answers the following statement: “I feel that since September 2010, the opportunity to improve accessibility in my community is...”

- ☐ Non-existent
- ☐ Very low
- ☐ Low
- ☐ Medium
- ☐ High
- ☐ Very high

38. Since the time of the September 2010 earthquakes, do you feel the opportunity to improve accessibility in your community has:

- ☐ Decreased
- ☐ Not changed
- ☐ Increased

39. To what extent do you feel confident that:

| | Not at all confident | Not very confident | Neutral | Confident | Very confident | Don't know |
|--|----------------------|--------------------|---------|-----------|----------------|------------|
| Central government (e.g. CERA) is making earthquake recovery | ○ | ○ | ○ | ○ | ○ | ○ |

| | | | | | | |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| decisions that are in the best interests of rebuilding an accessible city? | | | | | | |
| Local council is making earthquake recovery decisions that are in the best interests of rebuilding an accessible city? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Building developers are making earthquake recovery decisions that are in the best interests of rebuilding an accessible city? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

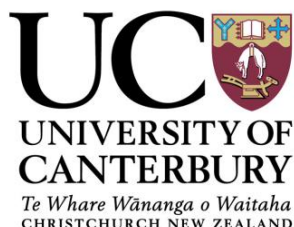
40. All things considered, what impact has the Christchurch sequence of earthquakes had on you?

(select one):

- ☐ None
- ☐ Some impact
- ☐ Moderate impact
- ☐ Significant impact

40. Do you have any other comments you would like to make about community inclusion following the Canterbury earthquakes?

Appendix N Phase Two email request to disability organisations for permission to circulate invitations.



Dear (organisation name),

My name is John Bourke, a wheelchair user and a doctoral student at the University of Canterbury.

I am conducting a study that seeks to survey people who use wheelchairs regarding their experience of community inclusion in the four years following the 2010/11 Canterbury earthquakes. This information can help local authorities understand the important factors for wheelchair users as communities rebuild.

I hope to recruit participants with the help of organisations such as yours.

Would you be happy to circulate the attached invitation amongst any of your members who use a wheelchair as their main form of mobility? Anyone who is interested in participating can use the details on the invitation to contact me for a link to the survey.

Please reply to this email to let me know whether or not you are happy to circulate this invitation to your members. On hearing back from you, if you are happy to help, I will get back in touch to provide more information about what the study involves.

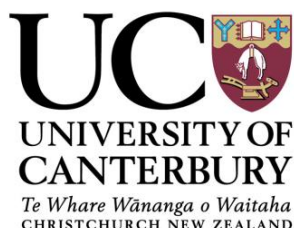
Your consideration of this request is greatly appreciated. If you have any questions please do not hesitate to contact me.

Kind regards,

John Bourke

Ph.D Candidate
School of Health Sciences
College of Education, Health, and Human Development
University of Canterbury
John.bourke@pg.canterbury.ac.nz
021 112 5596

Appendix O Phase Two participant information sheet (RDS).



Rebuilding following the Canterbury earthquakes: Wheelchair users experience of community inclusion.

INFORMATION SHEET FOR PARTICIPANTS

This survey seeks to understand how people who use wheelchairs have experienced community inclusion in the four years following the 2010/11 Canterbury earthquakes. This information sheet tells you who is conducting the study, the type of participants we are hoping to recruit, and what is involved if you do choose to take part. Please take the time to read through the information and feel free to contact one of the investigators for more information before making a decision (contact details are at the bottom of the last page).

Who is doing the study?

Hi there, my name is John Bourke and I am the principal investigator for this study. This study forms part of my doctoral research at the University of Canterbury. I have been using a power wheelchair as my main form of mobility after having a spinal cord injury in 2005. My supervisors for this project are Professor Philip Schluter (University of Canterbury), Associate Professor Jean Hay-Smith (University of Otago) and Dr Deborah Snell (Burwood Academy of Independent Living).

Aim of the survey

For this study I aim to survey people who use wheelchairs regarding their experience of community inclusion in the four years following the 2010/11 Canterbury earthquakes. Simply put, community inclusion means being able to interact with the people and in the places that are important to you. This information can help local authorities understand the important factors for wheelchair users as communities rebuild.

What types of participants are required?

I am interested in surveying people who use a wheelchair as their main form of mobility, reside in New Zealand, are 16 years or older, are able to read English, and have an operational email account and access to the internet.

What will you be asked to do?

If you agree to take part in the survey, follow the link in this email which will take you to the survey on the Survey Monkey™ website. The survey should take around 20 to 30 minutes to complete. Once you complete the survey we would really appreciate your help to find 3 other people to complete this survey. To do this I will send you three codes along with instructions

on how to email one code to each person so they can complete the survey. This type of survey and recruitment is called a Respondent Driven Survey approach.

Benefits of the study

When you complete the survey you will automatically enter the draw to win an iPad (funded by the University of Canterbury PhD student research fund allocation). You get one entry into the draw for completing the survey yourself. You can also get up to three more entries if those you invite to take part also complete the survey – total of 4 entries in all.

Although there are no other direct benefits from taking part, we also hope that the results of this study will highlight factors important to people who use wheelchairs as communities rebuild following natural disasters such as the 2010/11 Canterbury earthquakes.

What will happen to the information collected?

All information you enter into the survey will be kept private and secure. Your email address will only be known by myself and kept on a password-protected computer. All other information you submit will be converted into numbers so that anyone else needing to use the data, such as a statistician, will not be able to identify you. No identifying data will be presented in my doctoral thesis or any other research outcomes from this survey. The information you enter into the survey will not be passed on to any other parties or used for any other purpose apart from this study. The data will be kept in a locked cabinet for 10 years before being destroyed. This is standard practice for research.

Risks of the study

We understand that the survey will ask you about aspects relating to the 2010/11 Canterbury earthquakes and there is a chance this might be upsetting. You can stop the survey at any time. If you become concerned with any aspect of this study, or the subject of the earthquakes causes any distress, the following organisations can provide advocacy and assistance:

Health and Disability Services Consumer Advocate

The Health and Disability Advocacy can assist you with making sure your rights are respected. An advocate can listen to your concerns, provide information on your rights, and provide practical support regarding your options. To contact a Health and Disability Services Consumer Advocate, free phone 0800 555 050 for a list of free advocates in your area, or check <http://advocacy.hdc.org.nz/find-an-advocate.aspx>).

The Canterbury Earthquake Support Line

Canterbury Earthquake Support is a free and confidential service designed to support people following the Canterbury earthquakes. A coordinator can provide you with information and connect you with a wide range of services that offer practical information, support, and advice. You can contact the Canterbury earthquake Support Line on 0800 777 846

The University of Canterbury Human Ethics Committee

The University of Canterbury Human Ethics Committee can help with any ethical concerns regarding the conduct of the study. Please address any concerns to the University of Canterbury's Human Ethics Committee via human-ethics@canterbury.ac.nz

If taking part in the survey brings up any distressing issues and you would like more support, one of my co-investigators (Dr Deborah Snell) is a registered clinical psychologist and would be happy to provide you with information about where to go to get help. Her contact information is provided below.

Where can I get more information about the study?

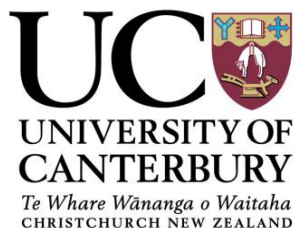
John Bourke
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(03) 364 2987 extension 4128

Professor Philip Schluter
School of Health Sciences
University of Canterbury
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(03) 364 2987 extension 44357

Associate Professor Jean Hay-Smith
Rehabilitation Teaching and Research Unit,
University of Otago
jean.hay-smith@otago.ac.nz
(03) 474 0999

Dr Deborah Snell
Academic Director
Burwood Academy of Independent Living (BAIL)
Private Bag 4708
Christchurch 8140
debbie.snell@burwood.org.nz
(03) 383 6871

Appendix P Phase Two participant recruitment email (RDS).



Hello,

Thank-you very much for completing the survey: *Wheelchair users' experience of community inclusion following the Canterbury earthquakes*. You are now entered into the draw to win an iPad! This will be drawn on Monday the 28th of March 2016 and the winner notified by email.

We would really appreciate your help to find 3 other people to complete this survey. These people must use a wheelchair, live in New Zealand, and be over 16 years old. Below are three codes - please email **one code** to each person so they can complete the survey.

Your 3 codes are:

1234
5678
9101

Simply email one of the above codes, along with the following link to the survey to each of the three people you have identified: www.examplesurvey.com (right click on this link and select 'copy'. Then in the new email right click in the text box and select 'paste').

Every time a person that you invite to take part also completes the survey – you will receive another entry into the iPad draw – a potential total of 4 entries in all.

If you have any questions regarding this process, please ring me on 021 xxx xxxx Mon-Fri, 12pm-5pm.

Once again, your participation in this study is greatly appreciated. Your feedback will be very important in helping local authorities understand the important factors for wheelchair users as communities rebuild.

Kind regards,
John Bourke

Ph.D Candidate
School of Health Sciences
College of Education, Health, and Human Development
University of Canterbury
John.bourke@pg.canterbury.ac.nz
021 xxx xxxx

Appendix Q Phase Two ethics amendment letter (convenience sampling).



HUMAN ETHICS COMMITTEE

Secretary

Telephone: +64 03 364 2987, Extn 45588

Email: human-ethics@canterbury.ac.nz

Ref: HEC 2015/117

20 January 2016

John Bourke
School of Health Sciences
UNIVERSITY OF CANTERBURY

Dear John

Thank you for your request for an amendment to your research proposal "Rebuilding following the Canterbury earthquakes: wheelchair users' experience of community inclusion (Phase two)" as outlined in your email dated 18th January 2016.

I am pleased to advise that this request has been considered and approved by the Human Ethics Committee.

Yours sincerely

A handwritten signature in black ink, appearing to read 'L. MacDonald'.

Lindsey MacDonald
Chair, Human Ethics Committee

Appendix R Phase Two generic survey invitation (convenience sampling)



Do you use a wheelchair?

If so you are invited to complete a University of Canterbury study that is exploring how wheelchair users have experienced community inclusion in the five years following the 2010/11 Canterbury earthquakes.

The survey will take around 15 minutes to complete, and all participants receive an entry into a draw to win an ipad!!!

The survey closes on Sunday March 13th, 2016.

To complete the survey, and find more information, please follow on the following link:

www.surveymonkey.com/r/chchinclusion

If you would like a hard copy of the survey sent to you, please contact John by email or phone using the details below:

john.bourke@pg.canterbury.ac.nz

021 112 5596

This research study has been approved by the Human Ethics Committee at the University of Canterbury (Ref 2015/117).

Appendix S Respondent Driven Sampling Publication

(Note – the responses to reviewers were written by John Bourke, submitted using Philip Schluter's account)



OBSERVATION ARTICLE

REVISSED Respondent driven sampling of wheelchair users: A lack of traction? [version 2; referees: 3 approved]

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v2 First published: 26 Apr 2016, 5:753 (doi: [10.12688/f1000research.8605.1](https://doi.org/10.12688/f1000research.8605.1))
Latest published: 26 Aug 2016, 5:753 (doi: [10.12688/f1000research.8605.2](https://doi.org/10.12688/f1000research.8605.2))

Abstract

Background: Internationally, wheelchair users are an emerging demographic phenomenon, due to their increased prevalence and rapidly increasing life-span. While having significant healthcare implications, basic robust epidemiological information about wheelchair users is often lacking due, in part, to this population's 'hidden' nature. Increasingly popular in epidemiological research, Respondent Driven Sampling (RDS) provides a mechanism for generating unbiased population-based estimates for hard-to-reach populations, overcoming biases inherent within other sampling methods. This paper reports the first published study to employ RDS amongst wheelchair users.

Methods: Between October 2015 and January 2016, a short, successfully piloted, internet-based national survey was initiated. Twenty seeds from diverse organisations were invited to complete the survey then circulate it to peers within their networks following a well-defined protocol. A predetermined reminder protocol was triggered when seeds or their peers failed to respond. All participants were entered into a draw for an iPad.

Results: Overall, 19 people participated (nine women); 12 initial seeds, followed by seven second-wave participants arising from four seeds. Completion time for the survey ranged between 7 and 36 minutes. Despite repeated reminders, no further people were recruited.

Discussion: While New Zealand wheelchair user numbers are unknown, an estimated 14% of people have physical impairments that limited mobility. The 19 respondents generated from adopting the RDS methodology here thus represents a negligible fraction of wheelchair users in New Zealand, and an insufficient number to ensure equilibrium required for unbiased analyses. While successful in other hard-to-reach populations, applying RDS methodology to wheelchair users requires further consideration. Formative research exploring areas of network characteristics, acceptability of RDS, appropriate incentive options, and seed selection amongst wheelchair users is needed.

Open Peer Review

Referee Status:

Invited Referees

1

2

3

REVISED

version 2

published
26 Aug 2016

report

report

report

version 1

published
26 Apr 2016

report

report

report

1

Jesse Kokaua, University of Otago
New Zealand

2

John F Smith, Kohn Kaen University
Thailand

3

A James O'Malley, Geisel School of
Medicine at Dartmouth USA

Discuss this article

Comments (0)

Corresponding author: John A. Bourke (john.bourke@pg.canterbury.ac.nz)

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Grant information: This paper reports on a section of JAB's doctoral research, which was supported by a University of Canterbury Doctoral Scholarship and a research scholarship from the Burwood Academy of Independent Living.

The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Competing interests: No competing interests were disclosed.

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REVISED Amendments from Version 1

In response to reviewers' suggestions, new information has been included briefly describing the fundamental assumptions of respondent-driven sampling, and the concept of sampling equilibrium: what it is, and why it was not reached in our study. New information has also been included clarifying recruitment and response rates. Finally, the Discussion has been expanded to consider how the strength of wheelchair users' social networks might have impacted our study, and more detailed recommendations have been included regarding the selection, and education, of seed participants.

See referee reports

Introduction

Robust epidemiological research generally requires data collection from representative samples of the population of interest, and effective modes of sampling contact are essential¹. Such effective modes can be difficult in hard-to-reach populations where no (or inadequate) sampling frames exist. Traditional chain-referral sampling approaches are inherently biased in their participant selection methods; a bias that is compounded as recruitment waves continue. An appealing alternative, Respondent Driven Sampling (RDS), was developed to counter these biases by employing specific data collection and statistical analysis methods which enable the derivation of valid population-based estimates²⁻⁴. RDS has traditionally been used to sample from 'hidden' populations with inadequate sampling frames, such as those with greater risk of HIV, including injecting drug users^{5,6}.

In brief, RDS is initiated by recruiting a handful of individuals who serve as 'seeds'. After completing the survey, seeds are then invited to recruit their peers to complete the same survey. To enhance recruitment, RDS employs 'dual incentives' whereby individuals are rewarded (usually monetary⁷) for both their participation, and the participation they can elicit from the person(s) they recruit². For RDS to provide unbiased population estimates, several assumptions need to be satisfied. Unlike convenience sampling, RDS requires that recruitment chains are traceable (via recruitment codes), that participants can provide an estimate of their network size (the number of people a person knows in the target population), and that participant's recruit randomly from their networks⁴. If these RDS assumptions are met, at some point sampling will reach a state of equilibrium, and useable unbiased data – independent from the initial seeds – can be gleaned.

Equilibrium is deemed to have been reached when there is relatively little variation in the sample proportions of key participant characteristics (such as age or sex) between successive measurement waves. The threshold for variation tolerance is determined prior to RDS implementation and a value of 2% is commonly employed^{8,9}. Equations for calculating equilibrium are described by Heckathorn (2002)¹⁰. Data produced before sampling equilibrium is reached are termed 'out-of-equilibrium' and are normally discarded due to their inherent biases. Unbiased population-based estimates use 'in-equilibrium data', data generated after equilibrium is reached so that recruitment theoretically represents a probabilistically determinable sample of network members.

Due to its appeal, the use of RDS has rapidly increased in two decades, with over 120 RDS studies reported in more than 20 countries with over 30,000 participants⁷. Despite wider adoption of RDS, and its successful application in many topic areas, concerns have been raised regarding whether RDS estimates hold in practice. For instance, some RDS estimates are more variable than expected¹¹, and some sampling patterns appear to violate core RDS assumptions^{5,12}.

The prevalence of wheelchair users has rapidly increased over the last half century due, in part, to advancing medical care, ageing populations, increasing community supports, increased prescription of wheelchairs, and changes in attitudes to disablement such that people may feel less stigmatised about using a wheelchair^{13,14}. Despite this, robust epidemiological research with this group in New Zealand and Australia is scant^{15,16}. Contacting wheelchair users in the community is challenging. Recruitment approaches are often limited to using disability organisations and personal contacts, which can differentially exclude many wheelchair users¹⁷. Consequently, wheelchair users may constitute a 'hidden population', under-researched and excluded from population estimates¹⁸. Furthermore, many countries, including New Zealand, have yet to establish registries of wheelchair users which could provide a reliable sampling frame^{16,18}.

Here we report our experience of applying a RDS methodology to a survey of wheelchair users in New Zealand. To our knowledge this is the first time RDS has been applied to people who use wheelchairs, and could potentially offer a significant new sampling approach in epidemiology and disability fields.

Methods

After a successful pilot with wheelchair users, this study employed a short internet-based national survey which was open from October 2015 until January 2016. Administered through the SurveyMonkey™ website, an information sheet and video were embedded within the survey preamble (see [Supplementary material](#)). The information sheet stated that informed consent was implied through the voluntary participation in the survey. Ethics approval was obtained from the University of Canterbury Human Ethics Committee (reference HEC 2015/117). Eligibility criteria included: wheelchair use as the primary form of mobility; being a New Zealand resident; aged 16 years or more; being able to read English; having internet access; and, having an operational email account.

Invitations seeking 'seed' participants were circulated to various national disability organisations serving members with a range of impairments that lead to wheelchair use. People expressing interest in being seeds contacted the researcher, who confirmed eligibility and then sent a recruitment code and a link to the survey website. Once a participant completed the survey, they were thanked and emailed three unique recruitment codes. Participants were asked to recruit a maximum of three other wheelchair users, following Heckathorn's (1997) recommendations². This limit of three was premised on two primary reasons: to ensure that a broad array of participants are recruited; and, to prevent the emergence of semi-professional recruiters. Participants were asked to email one code

and the survey link to three other persons they knew who were likely to satisfy the eligibility criteria. This process was envisaged to continue for multiple recruitment waves. Participation was incentivised (an entry into a draw to win an iPad); one entry for completing the survey, and another when each person they recruited completed the survey. Recruitment chains were tracked through tracing the recruitment codes. A predetermined reminder protocol was triggered when seeds or their peers failed to respond.

Results

Twenty wheelchair users expressed interest in participating as seeds, of whom 12 completed the survey (60% response rate). All 12 seeds were asked to recruit a maximum of three wheelchair users. Only four seeds were successful in recruiting further participants (three seeds each recruited two participants, and one seed recruited one participant), accumulating in a total of seven first wave participants. Despite all seven first wave participants being asked to recruit a maximum of three wheelchair users, using a clearly stated invitation and reminder protocol, no second wave participants completed the survey. Thus, the final sample was composed of 19 wheelchair users. Mean age of participants was 55.6 years (range: 28–73 years), and nine were women. Survey completion time ranged between 7 and 36 minutes.

Our recruited sample of 19 wheelchair users, however, failed to satisfy the requirements needed to reach equilibrium; the point at which the sample composition becomes independent of the initial seeds, thereby enabling the calculation of unbiased population estimates⁴. This failure stems from the study's premature termination, where only one measurement wave was completed. Even in the best-case scenario where equilibrium is reached in the smallest possible number of waves, namely one, no useable data could be produced after equilibrium. Furthermore, when only a single wave is conducted, all participants are within a single degree of separation from the seed participants accessed by the researcher. Such a sample lacks what Heckathorn terms 'sociometric depth' and it would, in all likelihood, fail to be representative of the entire hidden population¹⁰. For these reasons, an empirical assessment of equilibrium was not formally undertaken here, as it was both conceptually and statistically impossible for the data captured within this study to be in-equilibrium.

Discussion

Despite a rigorous recruitment process and offering incentivising participation, our use of RDS failed as an effective sampling approach amongst wheelchair users in New Zealand. There are a number of possible explanations as to why this occurred. The target population of the study was novel compared with hidden populations generally targeted by RDS studies. Research using RDS typically samples stigmatised populations, such as those with greater risk of HIV, including injecting drug users⁵, men who have sex with men^{12,19}, and sex workers²⁰. Wheelchair users have experienced increased integration into many societies in recent years and are arguably less stigmatised when compared to populations traditionally sampled using RDS. Populations experiencing greater

stigma may have a tendency to establish stronger social and internal networks, helping to facilitate the RDS requirement that the population being sampled has sufficiently strong internal networks which enable the random recruitment of other members of the population. With no literature to our knowledge regarding the internal networks of wheelchair users, it is unknown whether wheelchair users would satisfy the random recruitment criteria of RDS. Although the precise mechanism by which perceived stigma might affect RDS participation is unknown it, nonetheless, remains noteworthy. Second, the use of an unguaranteed reward (entry into a draw for an iPad) for survey completion has not been previously reported in RDS studies. This lack of guaranteed reward may have influenced participation. In addition, RDS studies often offer participants additional non-monetary free services related to the mitigation of HIV risk through counselling and educational material⁷.

Exploring the areas of network characteristics, acceptability of RDS, appropriate incentive options, and seed selection have all been suggested as important for assessing the feasibility and appropriateness of RDS in certain populations²⁰. Here, critical feedback on the appropriateness of the incentives, RDS methodology, elicitation mechanism and platform, and the survey itself was obtained from the pilot group – but not from the seeds. Formative research regarding specific seed selection is warranted. First, we recommend judiciously selecting diverse seeds who have large social networks, which should facilitate positive growth of recruitment chains. This increases the chances of participants with diverse characteristics being recruited and helping to avoid the exclusion of isolated subpopulations and individuals. It also helps to increase the speed at which sampling equilibrium can be reached⁹. Indeed, one RDS study exploring people who inject drugs in Sydney Australia reported that 80% of their participants resulted from one seed²¹. Second, meeting with seeds to provide greater education regarding goals and protocol of the survey might have improved the recruitment rates of our survey. Providing greater education to seeds might have increased their commitment to the goals of the survey, increasing the chances that seeds will report favourably about the survey, accurately explain the survey goals, and be motivated to pass on all three recruitment codes⁹. Despite the traditionally low response rates and impersonal nature of electronic surveys¹, administering surveys electronically is becoming more feasible and successful with populations who use wheelchairs²², and having informed and enthusiastic seeds might have encouraged greater response rates. Until such time as these and other factors, and their implications for recruitment, are better understood we feel that using RDS for recruiting wheelchairs users may have limited merit, and recommend formative research to optimise success.

Conclusions

Wheelchair users are an increasingly prevalent population in society who often lack an adequate sampling frame, and sampling approaches enabling valid population based estimates are becoming increasingly necessary. This paper reported the failure

of RDS to survey wheelchair users. Despite the unsuccessful recruitment in this study, further research exploring the application of RDS with wheelchair users is recommended before discounting this sampling approach in this population.

Data availability

Data are available upon request from the corresponding author to protect participant identity. Demographic data will be pooled to protect participant identity, as individual-level demographic data could be theoretically traceable due to the small sample size, and suspected small national population of wheelchair users.

Consent

All participants were informed that the voluntary completion of the survey implied informed consent, including for the publication of survey data.

Supplementary material

Internet-based national survey.

[Click here to access the data.](#)

Information sheet.

[Click here to access the data.](#)

Author contributions

All authors contributed to the design of the study. JAB conducted the data collection and prepared the first draft of the manuscript. All authors contributed to subsequent drafts and the final manuscript.

Competing interests

No competing interests were disclosed.

Grant information

This paper reports on a section of JAB's doctoral research, which was supported by a University of Canterbury Doctoral Scholarship and a research scholarship from the Burwood Academy of Independent Living.



The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

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Open Peer Review

Current Referee Status:   

Version 2

Referee Report 22 September 2016

doi:[10.5256/f1000research.10247.r15906](https://doi.org/10.5256/f1000research.10247.r15906)



Jesse Kokaua

Pacific Islands Research & Student Support Unit, University of Otago, Dunedin, New Zealand

The changes the authors have made have addressed the recommendations I had made for the first version.

I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Competing Interests: No competing interests were disclosed.

Referee Report 12 September 2016

doi:[10.5256/f1000research.10247.r16242](https://doi.org/10.5256/f1000research.10247.r16242)



A James O'Malley

Department of Biomedical Data Science and The Dartmouth Institute of Health Policy and Clinical Practice, Geisel School of Medicine at Dartmouth, Lebanon, NH, USA

I have read the revised article and feel that the authors have responded to my concerns as well as possible given the space limitations. As such, I am willing to change my decision to Approved.

I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Competing Interests: No competing interests were disclosed.

Referee Report 05 September 2016

doi:[10.5256/f1000research.10247.r16076](https://doi.org/10.5256/f1000research.10247.r16076)



John F Smith

Postgraduate Tropical Medicine Program, Faculty of Medicine, Kohn Kaen University, Khon Kaen, Thailand

I agree with the revisions, and therefore change my recommendation to Approved.

I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Competing Interests: No competing interests were disclosed.

Version 1

Referee Report 11 July 2016

doi:[10.5256/f1000research.9259.r14896](https://doi.org/10.5256/f1000research.9259.r14896)



A James O'Malley

Department of Biomedical Data Science and The Dartmouth Institute of Health Policy and Clinical Practice, Geisel School of Medicine at Dartmouth, Lebanon, NH, USA

Title and Abstract: The title is catchy and appropriate given the content of the article.

Article content: The article is very well written and is easy to read and follow. The article would be much improved if it included an introduction to respondent drive sampling (RDS) with particular emphasis on the assumptions required for RDS to work (reaching equilibria and otherwise) written in clear terms to a lay audience. Describe what it means for the sampling process to be in equilibrium. Currently, readers do not have the necessary information to reach an informed conclusion as to why RDS did not work well in this instance or to assess whether it is applicable to their own work.

The rationale for RDS assumes the existence of a social network in which the probability of a tie between a wheelchair user and a randomly selected wheelchair user exceeds the probability of a tie between a wheelchair user and a nonuser wheelchair user. What evidence that this is true? Do wheelchair users have sufficient social and other relationships importantly enough for them to be able to name sufficient other wheelchair users for the next round of sampling. Is it possible that many wheelchair users are isolates (in the network sense) because they are highly functional in everyday life and thus have reduced need for a community of wheelchair users? I don't know the answers to these questions and still don't as the needed background information is not provided in the article.

It would have been helpful to have been told the current state of knowledge about social networks among wheelchair users along with a connection of such knowledge to the assumptions under which RDS can yield unbiased population-level inferences. I would like to see some discussion of how RDS handles scenarios such as isolates in the wheelchair user network. Presumably, the only way such individuals make it into the sample is if they were randomly selected in the first (i.e., seed) wave.

Please add some general intuition for how RDS yields unbiased population-level estimates. Discuss the role of and derivation of individuals' sampling probabilities and thus sampling weights for computing population estimates. For example, the work of Thompson (2006a, 2006b, 2003, 2000 – see below – the 2012 text on Sampling and recent arXiv contributions) should be reviewed and used to inform the article.

References:

1. Thompson, Steven K. Targeted random walk designs. *Survey Methodology* 2006. 32:11-24

2. Thompson, Steven K. Adaptive web sampling. *Biometrics* 2006. 62:1224-1234
3. Chow, Mosuk, Thompson, Steven K. Estimation with link-tracing sampling designs - A Bayesian approach. *Survey Methodology* 2003. 29:197-205
4. Thompson, Steven K., Frank, Ove. Model-based estimation with link-tracing sampling designs. *Survey Methodology* 2000. 26:87-98

Data (if applicable): Details about the design/data for the study are lacking. It is stated that 20 wheelchair users were the initial seeds of which 12 agreed to participate (60% response rate). It then appears as though 4 of these 12 participants culled 7 further participants in the second stage of sampling. Question: Did the remaining 8 seeds not generate any wheelchair users (i.e., does the enrolment rate for the second stage equal 7/12) or was the plan to only ask 33% of the initial seeds for links to trace (in which case the enrolment rate is 7/4)? In the third stage, there was no addition to the sample-size. Were the 7 participants who entered at the second stage each asked to name other wheelchair users; is the enrolment rate at the third stage 0/7 or 0/x, where $x < 7$? Was there any limit as to how many wheelchair users a seed to subsequently enrolled person could name? A lot of these questions would be answerable if the design of the RDS was described in the article!

Conclusions: The discussion makes a number of good points that have appear sound and logical. The primary point made is that the current study may have failed because the wheelchair user population has different characteristics from populations where RDS has been used successfully. This is a valid point. But shouldn't this point have been considered when the study was design? Was there any prior information to inform the parameters of the RDS design? Maybe RDS would work quite well for the wheelchair user population as long as the number of initial seeds is much greater than 20. A more positively-framed Discussion might leave readers with a more balanced appreciation for using RDS in their own studies of wheelchair users or other new populations.

I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Competing Interests: No competing interests were disclosed.

Author Response 23 Aug 2016

Philip Schluter, University of Canterbury

Thank you greatly for your prompt, encouraging, and constructive feedback on our paper. Together with the comments made by the other two reviewers, your feedback has resulted in what we feel is a much improved paper.

We would like to take this opportunity to make two notes. [1] The original submission was restricted to 1000 words in total – but, with permission from the journal, this constraint has been relaxed and we are able to include more material. This means we are able to broaden discussion of relevant issues and thus strengthen the manuscript. [2] This paper was submitted to the journal as an 'observation article', defined as: *Observation Articles allow the description of a novel observation that may be unexpected, and possibly currently without explanation. An observation can be a phenomenon that has been identified in field work, in the laboratory or through experimental analysis* (see: <http://f1000research.com/for-authors/article-guidelines/observation-articles>).

Title and Abstract: The title is catchy and appropriate given the content of the article.

Thank you for the positive comment.

Article content: The article is very well written and is easy to read and follow. The article would be much improved if it included an introduction to respondent drive sampling (RDS) with particular emphasis on the assumptions required for RDS to work (reaching equilibria and otherwise) written in clear terms to a lay audience. Describe what it means for the sampling process to be in equilibrium. Currently, readers do not have the necessary information to reach an informed conclusion as to why RDS did not work well in this instance or to assess whether it is applicable to their own work.

We thank the reviewer for describing our article as well written and easy to read and follow. We agree that an introduction to RDS would improve the article. Our original submission was limited by word restrictions and article scope, as outlined above. However, in this revision, we have included more details. Specifically, we have included text in the Introduction section (see second paragraph) providing a brief introduction to RDS, and describing equilibrium (see third paragraph). We have expanded the Results section (second paragraph) to describe why equilibrium was not reached in our study.

The rationale for RDS assumes the existence of a social network in which the probability of a tie between a wheelchair user and a randomly selected wheelchair user exceeds the probability of a tie between a wheelchair user and a nonuser wheelchair user. What evidence that this is true?

We had no evidence to suggest this was true or false and felt on balance that the use of RDS in our study was warranted as there was a reasonable enough chance that it could be true without evidence to the contrary. Conducting a revised search on PubMed, Google scholar, and Science Direct, we could find no literature explicitly addressing this issue (we have included a sentence in the first paragraph of the Discussion section describing this).

Do wheelchair users have sufficient social and other relationships importantly enough for them to be able to name sufficient other wheelchair users for the next round of sampling. Is it possible that many wheelchair users are isolates (in the network sense) because they are highly functional in everyday life and thus have reduced need for a community of wheelchair users? I don't know the answers to these questions and still don't as the needed background information is not provided in the article.

This is indeed possible. The fact that a person uses a wheelchair does by no means infer that they know other people who use wheelchairs, let alone have strong internal networks with other wheelchair users. With respect to these questions we have included new text in the Discussion section (see first paragraph) regarding stigma and whether or not wheelchair users have sufficiently strong internal networks that enable random recruitment of other wheelchair users.

It would have been helpful to have been told the current state of knowledge about social networks among wheelchair users along with a connection of such knowledge to the assumptions under which RDS can yield unbiased population-level inferences. I would like to see some discussion of how RDS handles scenarios such as isolates in the wheelchair user network. Presumably, the only way such individuals make it into the sample is if they were randomly selected in the first (i.e., seed) wave.

As noted above, the current state of knowledge regarding the social networks among wheelchair users is unknown. As a result we cannot know if some wheelchair users are isolates. RDS theory assumes that the population being sampled comprises of a complete social network component, so in theory every person within their population has a probability of being sampled. In practice, to overcome isolated subpopulations, it is recommended that seeds from diverse subpopulations be selected. We have included a sentence to this effect in the second paragraph of the Discussion section.

Please add some general intuition for how RDS yields unbiased population-level estimates. Discuss the role of and derivation of individuals' sampling probabilities and thus sampling weights for computing population estimates.

Due to original word count, we had not included information clarifying that question two of our survey asked participants to provide an estimate of their network size (a requirement of RDS). Had our study produced in-equilibrium data (see new text in second paragraph in Introduction section, and new text in second paragraph of the Results section), sampling weights would have been allocated accordingly with those with smaller social network sizes being given a higher weight.

For example, the work of Thompson (2006a, 2006b, 2003, 2000 – see below – the 2012 text on Sampling and recent arXiv contributions) should be reviewed and used to inform the article.

References:

1. Thompson, Steven K. Targeted random walk designs. *Survey Methodology* 2006. 32:11-24.
2. Thompson, Steven K. Adaptive web sampling. *Biometrics* 2006. 62:1224-1234.
3. Chow, Mosuk, Thompson, Steven K. Estimation with link-tracing sampling designs - A Bayesian approach. *Survey Methodology* 2003. 29:197-205.
4. Thompson, Steven K., Frank, Ove. Model-based estimation with link-tracing sampling designs. *Survey Methodology* 2000. 26:87-98.

Thank you greatly for suggesting these references, which were reviewed and indeed helped with our thinking. Because our study failed to produce in-equilibrium data that warranted further analysis and consideration of sampling weights and sampling probabilities, substantial engagement with the topics in these papers was felt to be beyond the scope of our paper.

Data (if applicable): Details about the design/data for the study are lacking. It is stated that 20 wheelchair users were the initial seeds of which 12 agreed to participate (60% response rate). It then appears as though 4 of these 12 participants culled 7 further participants in the second stage of sampling. Question: Did the remaining 8 seeds not generate any wheelchair users (i.e., does the enrolment rate for the second stage equal 7/12) or was the plan to only ask 33% of the initial seeds for links to trace (in which case the enrolment rate is 7/4)?

All 12 seeds were asked to recruit 3 peers and for links to trace. Despite this, 8 seeds did not generate any more participants. The enrolment rate was 7/12. To clarify recruitment/response rates, text has been included in the first paragraph of the Results section.

In the third stage, there was no addition to the sample-size. Were the 7 participants who entered at the second stage each asked to name other wheelchair users; is the enrolment rate at the third stage 0/7 or 0/x, where $x < 7$?

The enrolment rate was 0/7. All 7 participants were asked to recruit 3 peers and for links to trace, but no participants were recruited. To clarify recruitment/response rates, text has been included in the first paragraph of the Results section.

Was there any limit as to how many wheelchair users a seed to subsequently enrolled person could name? A lot of these questions would be answerable if the design of the RDS was described in the article!

Thank you for raising this issue. All seeds and subsequent participants were asked to recruit a maximum of 3 peers and for links to trace. Heckathorn (1997) recommends that each respondent is limited to 3 ID codes to pass on to others, to ensure that a broad array of participants is recruited, and to prevent the emergence of semi-professional recruiters. We have now included two sentences describing this in the second paragraph in the Methods section.

Conclusions: The discussion makes a number of good points that have appear sound and logical. The primary point made is that the current study may have failed because the wheelchair user population has different characteristics from populations where RDS has been used successfully. This is a valid point. But shouldn't this point have been considered when the study was designed?

Yes, a valid point. In retrospect the potential impact of this point could have attracted greater consideration. However, we had no evidence to suggest it would be detrimental to the success of our employment of RDS. We also acknowledged that our application of RDS with wheelchair users was unprecedented and novel, and many outcomes were simply unknown. In the absence of any reliable sampling frame or registry, we believed the potential success amongst this population (on balance) was greater than the risks.

Was there any prior information to inform the parameters of the RDS design? Maybe RDS would work quite well for the wheelchair user population as long as the number of initial seeds is much greater than 20. A more positively-framed Discussion might leave readers with a more balanced appreciation for using RDS in their own studies of wheelchair users or other new populations.

Since our employment of RDS, a number of points, that may have improved our experience, have been considered. These include selecting more diverse seeds, and meeting with seeds to provide more information to them. To summarise these points, new text has been included our revised manuscript (see second paragraph in Discussion section).

Competing Interests: No competing interests to disclose.

Referee Report 13 June 2016

doi:[10.5256/f1000research.9259.r14016](https://doi.org/10.5256/f1000research.9259.r14016)



John F Smith

Postgraduate Tropical Medicine Program, Faculty of Medicine, Kohn Kaen University, Khon Kaen, Thailand

I support indexing this article as it appears to be a first-time test of the utility of Respondent Driven Sampling (RDS), a relatively novel sampling procedure, on a new "hidden" (hard to easily access) population--wheelchair riders. In this case it was not successful in recruiting sufficient respondents, but reporting that, and possible reasons for that outcome, could be useful for refining usage of the procedure.

I think the title and abstract are clear and provide good insight into the major points of the paper.

In addition to the possible reasons for low returns provided by the author I think it would be useful to include consideration of;

1. The typically low returns from internet surveys compared to face to face and pencil and paper surveys (see 1,2,3). It is possible that promoting an internet survey was just insufficient to motivate the "seeds", or the second wave recruits, to recruit more members into the network, even with an iPad reward incentive.
2. Elaborating on the "stigmatization" issue raised in the discussion. The "mechanism by which perceived stigma may effect RDS sampling" rather than being unknown, may well be that other groups e.g., drug users, "men who have sex with men"(MSM), sex-workers etc as a result of stigma, may have stronger social networks and obvious gathering spaces and be easier to access via seeds. Seeds with these groups are often "leaders", advocates who are "out", support group leaders, health service liaison/volunteer workers who move easily within those communities, social gatherings, entertainment or work spaces. There are not the same social pressures for wheelchair riders to have these group social connections or common activities.
3. Methodological point. The article focuses on RDS's value for accessing representative population samples for research seeking normative and epidemiological data and concomitant importance of avoiding/controlling sample selection bias. However, RDS could also be valuable for accessing qualitative data e.g., wheelchair riders' views/experiences with public policies/services etc where as wide a range of responses (variability) should be expected, indeed welcomed, rather than seen as requiring some statistical weighting or control procedure. Other forms of criterion for data "completeness" e.g., saturation could be used here. Another use for RDS is just to collect as large a sample as possible in hidden groups regardless of their representativeness. For example, RDS "seeds" have been used to recruit as many MSM as possible in "test and treat" outreach campaigns for blood testing for HIV and ante-retroviral treatment programs.

Overall a potentially useful addition to methodological literature on sampling procedures.

I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Competing Interests: No competing interests were disclosed.

Author Response 23 Aug 2016

Philip Schluter, University of Canterbury

Thank you greatly for your prompt, encouraging, and constructive feedback on our paper. Together with the comments made by the other two reviewers, your feedback has resulted in what we feel is a much improved paper.

We would like to take this opportunity to make two notes. [1] The original submission was restricted to 1000 words in total – but, with permission from the journal, this constraint has been relaxed and we are able to include more material. This means we are able to broaden discussion of relevant issues and thus strengthen the manuscript. [2] This paper was submitted to the journal as an 'observation article', defined as: *Observation Articles allow the description of a novel observation that may be unexpected, and possibly currently without explanation. An observation can be a phenomenon that has been identified in field work, in the laboratory or through experimental analysis* (see: <http://f1000research.com/for-authors/article-guidelines/observation-articles>).

I support indexing this article as it appears to be a first-time test of the utility of Respondent Driven Sampling (RDS), a relatively novel sampling procedure, on a new "hidden" (hard to easily access) population - wheelchair riders. In this case it was not successful in recruiting sufficient respondents, but reporting that, and possible reasons for that outcome, could be useful for refining usage of the procedure.

Thank you for recognising the novelty of this approach, together with your encouraging and supportive comments regarding our paper.

I think the title and abstract are clear and provide good insight into the major points of the paper.

Thank you.

In addition to the possible reasons for low returns provided by the author I think it would be useful to include consideration of;

1. *The typically low returns from internet surveys compared to face to face and pencil and paper surveys (see 1,2,3). It is possible that promoting an internet survey was just insufficient to motivate the "seeds", or the second wave recruits, to recruit more members into the network, even with an iPad reward incentive.*

Yes, this is indeed a valid consideration. In response, we have included a sentence the second paragraph in our revised discussion specifically referring to how more informed and enthusiastic seeds could have encouraged greater response rates, acting as a potential mitigation strategy against the impersonal nature of electronic surveys.

1. *Elaborating on the "stigmatization" issue raised in the discussion. The "mechanism by which perceived stigma may effect RDS sampling" rather than being unknown, may well be that other groups e.g., drug users, "men who have sex with men"(MSM), sex-workers etc as a result of stigma, may have stronger social networks and obvious gathering spaces and be easier to access via seeds. Seeds with these groups are often "leaders", advocates who are "out", support group leaders, health service liaison/volunteer workers who move easily within those communities, social gatherings, entertainment or work spaces. There are not the same social presses for wheelchair riders to have these group social connections or common activities.*

Yes, this is valid and interesting point, and was also raised by another reviewer. In response, we have elaborated on the stigma issue by including new text in the first paragraph in the Discussion

section addressing the area of perceived stigma, and whether or not wheelchair users have a sufficiently strong internal network that enable the random recruitment of other wheelchair users.

1. *Methodological point. The article focuses on RDS's value for accessing representative population samples for research seeking normative and epidemiological data and concomitant importance of avoiding/controlling sample selection bias. However, RDS could also be valuable for accessing qualitative data e.g., wheelchair riders' views/experiences with public policies/services etc where as wide a range of responses (variability) should be expected, indeed welcomed, rather than seen as requiring some statistical weighting or control procedure. Other forms of criterion for data "completeness" e.g., saturation could be used here. Another use for RDS is just to collect as large a sample as possible in hidden groups regardless of their representativeness. For example, RDS "seeds" have been used to recruit as many MSM as possible in "test and treat" outreach campaigns for blood testing for HIV and ante-retroviral treatment programs.*

The value of using the RDS in qualitative research is a very interesting concept, and could be raised in the Discussion. However, on balance we feel it may be beyond the scope of our paper here, which was to discuss our experience of unsuccessfully satisfying the requirements needed to produce a theoretically representative sample of the population with no sampling frame.

Overall a potentially useful addition to methodological literature on sampling procedures.

We appreciate these words and the additional references offered.

Competing Interests: No competing interests to disclose

Referee Report 09 May 2016

doi:[10.5256/f1000research.9259.r13572](https://doi.org/10.5256/f1000research.9259.r13572)



Jesse Kokaua

Pacific Islands Research & Student Support Unit, University of Otago, Dunedin, New Zealand

I think this paper has merit as a scientific publication, in that it adds to the body of research about RDS by its application to a "hidden" population, that by all accounts should be reasonable, but turned out to be not effective.

The abstract begins with a sentence that ends with a repeated point "rapid increasing life-span" and "accelerated general population ageing". One of those statements is redundant. Paragraph 2 of the introduction starts with international findings but does the second sentence beginning with "Despite this . . ." refer to the NZ experience, or outside of the US and UK?

I feel that some points could be expanded upon:

The authors could expand, in the introduction, how the method improves the validity of, and reduces biases in, population-based estimates over other methods.

Examples of typical target populations for this method that are introduced in the discussion should move

to the introduction, as it supports the novelty of this application.

I feel the results are two-fold. Firstly, the sample as described. I know its a moot point but I would be interested to know how big a sample is required to reach equilibrium.

Secondly, since this is a paper on the RDS, I would have liked to see a description of the total numbers of people approached in each wave, with eligible and ineligible participants. Thus reporting if the failure was a result of response, eligibility, or simply a lack of invitation to participate in subsequent waves.

This is an interesting application of a novel method of sampling from a group of people made hard-to-reach, it seems, as a result of their successful integration into contemporary New Zealand society. One characteristic of strongly stigmatised groups in New Zealand, such as those identified in the paper, are their tendency to establish strong internal networks, both informal and formal, that I feel would be useful to this type of methodology. It would be difficult for individuals with small networks to fulfill the random selection criteria for RDS. I take it that this may have influenced the less stigmatised wheelchair user population but it wasn't clearly stated if this was the case.

The paper reports a good example of where a useful method may not apply, in its initial format, to a particular interest group. However, it wasn't totally discounted as a potential approach but the reader is left without any suggestion as to how it might be modified to improve its take up, except for the suggestion of formative research, while fulfilling the assumptions required for RDS to provide unbiased population-wide estimates.

I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Competing Interests: No competing interests were disclosed.

Author Response 23 Aug 2016

Philip Schluter, University of Canterbury

Thank you greatly for your prompt, encouraging, and constructive feedback on our paper. Together with the comments made by the other two reviewers, your feedback has resulted in what we feel is a much improved paper.

We would like to take this opportunity to make two notes. [1] The original submission was restricted to 1000 words in total – but, with permission from the journal, this constraint has been relaxed and we are able to include more material. This means we are able to broaden discussion of relevant issues and thus strengthen the manuscript. [2] This paper was submitted to the journal as an 'observation article', defined as: *Observation Articles allow the description of a novel observation that may be unexpected, and possibly currently without explanation. An observation can be a phenomenon that has been identified in field work, in the laboratory or through experimental analysis* (see: <http://f1000research.com/for-authors/article-guidelines/observation-articles>).

I think this paper has merit as a scientific publication, in that it adds to the body of research about RDS by its application to a "hidden" population that by all accounts should be reasonable, but turned out to be not effective.

Thank you for your positive comments and summation. This, for us, was the basis for opting for the “novel observation” article type.

The abstract begins with a sentence that ends with a repeated point "rapid increasing life-span" and "accelerated general population ageing". One of those statements is redundant.

Although the intention was to make two important points, the first referring to wheelchair users and the second referring to the general population, we agree that this is unnecessarily confusing. We have revised this sentence to: “Internationally, wheelchair users are an emerging demographic phenomenon, due to their rapidly increasing life-span.”

Paragraph 2 of the introduction starts with international findings but does the second sentence beginning with "Despite this . . ." refer to the NZ experience, or outside of the US and UK?

This appears to be an international trend. However, to be clearer we have included “in New Zealand and Australia” and inserted an apposite reference.

I feel that some points could be expanded upon: The authors could expand, in the introduction, how the method improves the validity of, and reduces biases in, population-based estimates over other methods.

Agreed – indeed, a similar point was raised by another reviewer. Our original submission was limited in scope due to the word restrictions, as outlined above. However, in this revision, we have included more information and discussion. Specifically, we have included text providing a brief introduction to RDS (See second paragraph in Introduction section).

Examples of typical target populations for this method that are introduced in the discussion should move to the introduction, as it supports the novelty of this application.

Thank you for this comment; it indeed strengthens our introduction. In our revised manuscript we have included the following sentence with paragraph one of the Introduction: “RDS has traditionally been used to sample ‘hidden’ populations with inadequate sampling frames, such as those with greater risk of HIV, including injecting drug users.”

I feel the results are two-fold. Firstly, the sample as described. I know it's a moot point but I would be interested to know how big a sample is required to reach equilibrium.

We also felt that this information would strengthen our paper, but omitted it initially – due to the word count restrictions. In this version, within the Introduction, we now explicitly add an explanation about the concept of equilibrium and how it is reached (see third paragraph), while the second paragraph in the Results section explains specifically why our sample failed to satisfy the threshold for in-equilibrium data.

Secondly, since this is a paper on the RDS, I would have liked to see a description of the total numbers of people approached in each wave, with eligible and ineligible participants. Thus reporting if the failure was a result of response, eligibility, or simply a lack of invitation to participate in subsequent waves.

These details would be hard, if not ethically impossible, to determine. Consistent with RDS

protocol, an email was sent to people asking them to send on the invitation to three people, but there was no obligation for us (the researchers) to receive confirmation about whether all three recruitment codes were successfully allocated and distributed. Nevertheless, more information has been included in the Methods section (second paragraph) regarding how participants were asked to recruit three others, and the first paragraph in the Results section, which clarifies recruitment and response rates.

This is an interesting application of a novel method of sampling from a group of people made hard-to-reach, it seems, as a result of their successful integration into contemporary New Zealand society. One characteristic of strongly stigmatised groups in New Zealand, such as those identified in the paper, are their tendency to establish strong internal networks, both informal and formal, that I feel would be useful to this type of methodology. It would be difficult for individuals with small networks to fulfil the random selection criteria for RDS. I take it that this may have influenced the less stigmatised wheelchair user population but it wasn't clearly stated if this was the case.

Yes, this is valid and interesting point and was also raised by another reviewer. In response, we have included two sentences in the first paragraph of the Discussion section addressing the area of perceived stigma and whether or not wheelchair users have sufficiently strong internal networks that enable the random recruitment of other wheelchair users.

The paper reports a good example of where a useful method may not apply, in its initial format, to a particular interest group. However, it wasn't totally discounted as a potential approach but the reader is left without any suggestion as to how it might be modified to improve its take up, except for the suggestion of formative research, while fulfilling the assumptions required for RDS to provide unbiased population-wide estimates.

Thank you for this comment that will strengthen our paper. In response we have included more information in the second paragraph of the Discussion section about potential ways to improve similar studies, namely, selecting diverse seeds with larger networks and providing greater information and education to those seeds.

Competing Interests: No competing interests to disclose

Community inclusion of wheelchair users during the long-term recovery phase following the 2010/2011 Canterbury earthquakes

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